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**FACULTY OF SOCIAL SCIENCES**

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**Organ Trade in India  
- The Grey Area**

*Master thesis*

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**Subject: IEPS**

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## **Abstract**

The first ever organ transplant was successfully performed in the year 1954 making life after organ failure a possibility. Organ transplantation thus became a miraculous medical advancement. But it triggered bioethical concerns about commercially trading on organs for transplant. And this is an attempt to investigate the highlighted issue of organ trade particularly in India.

India passed an act to ban organ trade in 1994. Yet the country battles illegal organ trade and an acute organ shortage, even today. Through this work the objective is to trace the reasons behind the said issue by way of policy analysis and ethical analysis. And thereby propose appropriate solutions.

## **Abstrakt**

The first ever organ transplant was successfully performed in the year 1954 making life after organ failure a possibility. Organ transplantation thus became a miraculous medical advancement. But it triggered bioethical concerns about commercially trading on organs for transplant. And this is an attempt to investigate the highlighted issue of organ trade particularly in India.

India passed an act to ban organ trade in 1994. Yet the country battles illegal organ trade and an acute organ shortage, even today. Through this work the objective is to trace the reasons behind the said issue by way of policy analysis and ethical analysis. And thereby propose appropriate solutions.

## **Klíčová slova**

**Organ trade, Donor crisis, Deceased organ donation, Bioethics, Dharma**

## **Keywords**

**Organ trade, Donor crisis, Deceased organ donation, Bioethics, Dharma**

## **Declaration of Authorship**

I hereby declare that this thesis is my own work, based on the sources and literature listed in the appended bibliography. This thesis has not been used to obtain a different or the same degree. The thesis as submitted is 102,799 keystrokes long (including spaces) i.e. 62 manuscript pages.

Prague, May 19, 2017

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Pavithra Ramesh

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# Master Thesis Proposal

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## Proposed Topic:

<b>Organ Trade in India: The Grey Area</b>
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**Registered in SIS: Yes**

**Date of registration: 10.06.2016**

## Topic Characteristics / Research Question(s):

Bioethics is the study concerned with the implications of medical procedures, technologies and treatments from the perspective of ethics, philosophy, law and its implementation. It encompasses a wide range of ethical concerns in relation to organ transplants, genetic engineering, artificial reproduction, euthanasia etc. My thesis is an attempt to probe into certain ethical nuances amidst the technological advances in the field of medicine. Particularly, with respect to organ trade in India.

Since the origin of medicine the primal goals have followed the Hippocratic Oath of “*Cure sometimes, treat often, comfort always.*” (Adams 1891). The questions this perception of early medicine leaves us with are: Have we withdrawn from the compassion and ethics prescribed with the advent of advanced lab technology? What are the issues around organ trade in India? What causes these issues? And how can this be dealt with? The approach to pursue the answers for the above, revolves around the Indian policy that bans organ trade. The proposed work is intended to be an inquiry into the ban – In which the problem, process and outcomes of the policy are analyzed to evaluate its sufficiency. Alternatively, the removal of the ban or legalizing organ trade in India is analyzed from an ethical stand point. After the policy analysis of the ban and ethical analysis of legalizing organ trade, relevant solutions are proposed.

The solution cannot be to just ban the trade nor can it strike the other end of the spectrum and permit a completely free market for organs. Choosing from extremes would never work with the sensitivity at bay. A middle ground has to be struck. The need is to explore the in-between (grey area) rather than choose the extremes.

### **Working hypotheses:**

- 1: In India, the current policy ban on organ trade alone is insufficient.
- 2: Legalizing organ trade in India is not an alternative policy solution.

### **Methodology:**

The objective is to analyse the policy through a systemic method, arrive at the implications and further explore an alternative and propose solutions.

- 1: In India, the current policy ban on organ trade alone is insufficient.

Policy analysis of the 'Ban on Organ Trade' through the application of Institutional Analysis and Development Framework (2009) as developed by Elinor Ostrom and her colleagues at Indiana University

- 2: Legalizing organ trade in India is not an alternative policy solution.

Ethical analysis of legalizing organ trade through the application of Global and Indian Schools of thought. [a] The International Human Rights perspective – Global Ethics [b] A case study of Iran's model of organ trade [c] Application of principles of DHARMA - the Indian theory of morality and social life.

### **Outline:**

Introduction  
Theory & Methodology  
Literature Review

#### **Part I:**

Organ trade: setting the stage

- Organ Transplantation
- Organ Trade
- Organ Trade in India

#### **Part II:**

Why the current ban alone is insufficient?

- Status Quo
- Policy Outcomes
- Policy Analysis
- Policy recommendations

#### **Part III**

Why legalizing organ trade is not an option for India?

- Global legislation trend
- Ethical Stance
- Policy Recommendations

Conclusion

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## INTRODUCTION

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“Cure sometimes, treat often, comfort always.” (Adams 1849) is the motto that Hippocrates, the Greek father of medicine prescribes for its practice. But, with the advent of technology the field has inevitably also become about commerce. The above dichotomy is the crux of this study – ‘The case of organ trade in India’. The objective of this work is to investigate the complexities of organ trade in India, by probing into its policy and the ethical stance behind it.

Through this piece of work, the goal is to (1) Analyse the policy to ban organ trade in India (2) Explore the possibility of legalizing organ trade and thereby, make relevant policy recommendations. In pursuit of the goal the following arguments are made:

**1: In India, the current policy ban on organ trade alone is insufficient.**

We break-down the policy, its process and outcomes to understand why the nation battles with issues around organ trade, even after two decades post the ban.

**2: Legalizing organ trade in India is not an alternative policy solution.**

We invest in the ethical standpoint on the possibility of removing the ban to understand why it cannot be seen as an alternative.

*The above arguments on the ‘Ban’ and ‘Removal of the ban’ is not a case of black or white; but a case with the need to explore the extensive grey area.* The grey area in this context can be described as doing more than just banning organ trade. But, not resorting to legalizing it. The policy recommendations made are within the two parameters signifying the grey area that India could penetrate on this subject.

The work is segmented into three parts. Part I sets the stage for the two arguments highlighted above. While Part II and III explores the two arguments, subsequently making relevant policy recommendations.

## THEORETICAL BACKGROUND & METHODOLOGY

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While Part I of the paper acts as an introduction to the theme of study, Part II provides policy analysis and Part III presents an ethical analysis on the subject.

### **1: In India, the current policy ban on organ trade alone is insufficient.**

- Theoretically it is approached from a Public Policy perspective. The policy problem is traced from when it was a social problem to the time of policy implementation. After which, the policy outcomes are recorded and recommendations are made.
- Methodology: Policy analysis is pursued through the application of *Institutional Analysis and Development Framework* (2009) as developed by Elinor Ostrom and her colleagues at Indiana University.

### **2: Legalizing organ trade in India, is not an alternative policy solution.**

- The second argument is approached from Global and Indian ethical schools of thoughts. [a] The International Human Rights perspective – Global Ethics and [b] DHARMA - the Indian theory of morality and social life.

Methodology:

- The global trends in legislation of organ trade is analyzed from the International Human Rights Perspective.
- A case study on the Iran's model of organ trade is presented and compared with India
- A secondary survey is studied to understand the consequences of organ trade in India
- The principles of DHARMA are applied and a primary survey is presented to understand the ethical stance on organ trade in India.

## LITERATURE REVIEW

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The focus and flow of the study is approached from general to specific. Thus, its sources work at various layers, such as: [1] Bioethics [2] organ transplantation [3] organ trade and [4] organ trade in India. Bioethics being the underlying theme is appropriately drawn from during discussions on the subsequent layers as listed above. Organ transplantation and issues around it are presented to form the basis and to derive the causes of organ trade. The focus is then narrowed down from organ trade to organ trade in India.

**[1] BIOETHICS:** *“Bioethics, was to be a tool with which individuals and the societies they inhabit could answer questions of medical practice and the research that sometimes put those politely called “human subjects” at risk.”* (Koch 2012) Literature on the topic of bioethics is predominantly driven by the discussion on virtues with advent of technology and angle of commerce in medicine. The above quoted work of Tom Koch, titled “Thieves of Virtue” provides a basic bioethics series collaborating material from 1988 to 2008 to make the topics available for a wide audience. Most available materials indicate that ethical analysis of medical practices date back to the 1960’s (Ruddick 1998). Albert Jonsen’s ‘Birth of Bioethics’ helps understand the nature and evolution of bioethics (Jonsen 1998). They cover a variety of ethical concerns in medicine such as organ transplants, genetic engineering, artificial reproduction, euthanasia etc. The bottom line of such studies remain querying the ethics in different practices of modern medicine. Some discuss the topic from policy making perspective like Dan Brock (Brock 1987). The most influential material on bioethics of organ transplantation for this thesis is a journal made available at *The National Center for Biotechnology Information* archives - ‘Bioethics of organ transplantation’ (Caplan 2014) which analyzes the various policies around the topic and why they are inadequate. And further discusses the markets and

donation of organs. The author recently published yet another informative article on the topic of bioethics in organ transplant (Caplan and Purves 2017) which raises the ethical dilemma between transplant to save lives and transplant to improve the quality of life (e.g. facial transplant).

**[2] ORGAN TRANSPLANTATION:** Before investing in the topic of organ trade, organ transplantation and the issues around it are explored. An account of the first successful kidney transplant made in 1954 is presented in the Harvard Gazette, Health & Medicine (Powell 2011) recording it as a miracle. Several such stories instilling hope of life after organ failure are made available in materials published by organizations like the UNOS (United Network of Organ Sharing 2015). Such articles either aim to represent the advancement of medicine or to promote organ donation by publishing successful transplants. The mainstream content though, can be seen as two kinds. One that provides all the information about the process of transplant and various sources of organs. The other that discusses the issues around organ transplant such as the organ shortage and dilemmas in allocation of organs. The following journal articles fall under the second kind. ‘The Failure to Give: Reducing Barriers to Organ Donation’ (Childress 2001) and ‘Making organ donation a better deal’ (Kahn P. 2002). While ‘Ethics of Organ Transplantation’ (Center for Bioethics 2004) delivers a comprehensive account of both information about the process and the issues around it. On the whole, the information about organ shortage being an issue of organ transplant that is faced around the world is all pervasive and staple in related works. The information on the intensity of shortage in different parts of the world is available as data in bulletins of World Health Organization and World Medical Association etc. which make for the opening statement in all relevant works.

**[3] ORGAN TRADE:** Works on organ trade and specifically organ trafficking has largely been theoretical or discussion based. The discussions are furthered through ethical analysis and arguments around the crimes of organ trafficking. Primarily, such analysis either substantiates the needs and arrives at legalizing organ trade or contests the ethics and argue against legalizing organ trade. Articles of Bryan Caplan (B. Caplan 2009), David H. Howard (Howard 2007) and Michael Brooks (Brooks 2003) fall under the first category and support the option of commercial organ transplantation or legalizing organ trade by citing the move as a solution to both organ shortage and the cases of organ trafficking. Michael Brooks discusses free market for kidneys and Howard favours liberalization. Examples of the second category are works of Manfred Tietzel (Tietzel 2001) who offers a common-pool allocation of organs as a solution and Alberto Abadie, Sebastien Gay (Abadie and Gay 2004) who study the impact of presumed consent.

The proposition to legalize organ trade is seen as the occasionally raised solution while the majority of materials published on the subject of organ trade discuss the Human rights perspective and do not necessarily offer solutions. Amahazion (2016) discusses world culture, human rights and legislation which helps arrive at the global legislation trend. Another significant contributor to the human rights perspective is Nancy Scheper-Hughes, an organ detective who investigates organ trade across the world. (Scheper-Hughes 2005) Her works take the stand of developing countries being exploited in the organ market. Reflecting the same line of thought (Cho, Zhang and Tansuha 2009) provide an empirical study to support that globalization aids international human organ trafficking. Thus most of the sources present the case of organ trafficking as a global crime with a human rights perspective. Additional examples are (Jafar 2009), (Agrell and Glazer 2011) and (Ignatieff 2000). With Iran being the only country where organ trade is legal, considerable amount of literature presents the case of Iran and traces why its system



works. While (Ghods and Savaj 2006) provides the information on how the model works, (Crepelle 2016) attempts to represent the model as an effective solution and (Haghighi and Ghahramani 2006) breaks down the social circumstances that led and support organ trade in Iran.

The major drawback with respect to sources on organ trade is the lack of availability of empirical data. Despite most of the above listed works recording prevalence of illegal organ trade and crimes around it, there is no accurate data to gauge the intensity of such crimes. Some estimated data has been accessible through the WHO bulletins (Shimazono 2007) and UNOS factsheets. Apart from the two, the thesis draws from the article '*An empirical study on international human organ trafficking: effects of globalization*'

**[4] ORGAN TRADE IN INDIA:** The lack of available empirical data is even more profound when it comes to organ trade specifically in India. The data that is presented through the course of this study has been sourced from statistical booklets released by MOHAN foundation, which is an NGO that does several research work in the field of organ transplant and donation. Further, the statistics on cases against illegal organ trade have been retrieved from the 'Crimes in India' statistical handbook as published by the National Crime Records Bureau of the country (NCRB 2016). The downside to which is that, this data has been available only after 2014 due to the revision of the crime's status. The most primal source with respect to organ trade in India is that of Raj Chengappa's which was one of the earliest articles written on the topic (Chengappa 1990). The article elucidates exploitation of the economically weaker sections of the nation in commercial organ transplant before the ban was imposed. Since the article provides for an insight into the subject before the 1994 ban, it is a valuable source and can be seen referenced in most relevant works.

Subsequently, Cohen's work further records the plight of exploited donors and analyzes the issue through an ethical standpoint. Additionally investing in the social structure of the Indian communities. (Cohen Daedalus 1999 Fall). Another most vital source is the JAMA journal article on the economic and health consequences of selling a kidney in India (Goyal, Mehta and Schneiderman, et al. 2002). The authors published the results of a survey which indicated that most donors were not economically better off, but faced health deteriorations after selling a kidney.

The central aspect of organ trade in India is its policy ban. Works of (Haagen 2005), (Bhattacharya 2012) and (Dr. Srivatava 2013) throw light on the legislation around the ban. Mette Haagen's research paper applies discourse analysis from human rights and inequality-poverty perspectives. The work thus criticizes the effectiveness of the legislation but does not offer any solution. On the other hand, the paper 'Combating Organ Trafficking in India' (Bhattacharya 2012) arrives at the same conclusion, but proposes legalizing organ trade. The author fails to analyse the consequences of the said solution. The critique of available literature is that most of them concentrate purely on the exploitation of the poor, crimes of organ trafficking and the human rights issue. There is a lack of analysis of the policy ban beyond claims that it has loop holes. Especially, new amendments between 2008 and 2014 are hardly recognized or registered. As an exception, Dr. Sunil Shroff's report explains the 2014 amendment from the perspective of the medical society and this was published in the MOHAN foundation's website.

Finally, journal articles (Azeez 2015), (Jha 2014) and (Sinha 2012) help assimilate the nature and scope for various forms of organ donation in India. Thereby directing the thesis towards proposing solutions that are relevant.

PART I

# ORGAN TRADE IN INDIA

SETTING THE STAGE

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**Abstract:** *The following chapter introduces the theme of the study which is 'Organ Trade'. The introduction progresses from the topic of organ transplantation and the issues around it, to organ trade and further to organ trade specifically in India. Thus, explaining the policy problem*

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## I.1. ORGAN TRANSPLANTATION

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The United Network for Organ Sharing, a Non-Profit Organization based in the United states, that manages the nation's organ transplant system with the federal government under contract (United Network of Organ Sharing 2015) records the following story of hope on it's website as narrated by Whittney, a little girl under 10yrs of age.

*"Whittney has named her kidney 'Princess Chocolate Strawberry' and says the kidney donation means the world to her because "I can just be a normal kid now." (Stories of Hope 2015)*

Similar organizations across the globe record many more stories of hope and such stories have been made possible since 1954. The year was marked in the history of organ transplant with Harvard Medical School Professor Joseph Murray's successful kidney transplant operation on Richard Herrick a 23yr old coast guard; who could continue to lead a life with his twin brother's kidney (Powell 2011). During the times when organ failure often meant death sentence, the transplant was indeed a miracle. But, as described by Albert R. Jonsen *"The miracle was not an unalloyed grace."* (Jonsen 1998)

The case of Whittney, elucidates the miraculous aspect of the medical advancement – organ transplant; while, on the other end of the spectrum is the case of a middle aged woman in the slums of Ayynavaram, Chennai, India. *"I sold my kidney for 32,500 Rupees. What choices did I have? I would do it again if I had another to give. I would have to. That money is gone and we are in debt."* (Cohen Daedalus 1999 Fall) Said a woman who didn't want to be named in 1998, during her interview with Lawrence Cohen on the topic 'Selling-their-kidneys-to-survive'. Between the story of a little girl who named her new kidney and the story of a middle aged woman who sold her kidney to pay her debt, the narrative shifts from organ transplant to organ trade with an underlying theme of survival.

Organ transplantation has proved that it can save lives. But there are numerous concerns around organ trade, primarily ethical? To understand organ trade and its ethical concerns it is crucial to discuss a few issues around organ transplantation. Since these issues form the basis for organ trade.

### **I.1.A. ISSUES AROUND ORGAN TRANSPLANTATION:**

#### **i. Organ Shortage**

Primarily the issues around organ transplantation originate due to the acute shortage in the organs available for transplant. The number of donated organs have continued to stay fairly constant over time while the number of people needing organs continue to increase (Kahn P. 2002). Across the world, with respect to organs for transplant there remains a state of increasing demand and unmatched supply. To deal with the issues arising out of organ shortage, increasing the number of donor organs has been seen as a solution. However, the greatest threat that policies to increase organ donations pose are its implications. For example, possible motivation that could lead to organ farming.<sup>1</sup> (Center for Bioethics 2004, 20)

#### **ii. Distribution of available organs**

Further to the shortage of organs the issue of distributive justice erupts (Center for Bioethics 2004, 15). How to allocate the minimally available organs for transplant? How to decide the criticality of the case that requires a transplant? And many such questions come up. Various distributive justices like the '*Equal access distribution*' and the '*maximum benefit distribution*' make for the discussions on this debate. The former recommends first come, first serve & youngest to oldest. While the latter recommends sickest people first & longevity in transplant success as determining criteria for

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<sup>1</sup>Organ farming: practice of conceiving a child with the intention of aborting it for its organs (or) declaring premature brain deaths to harvest organs.

distribution (Center for Bioethics 2004, 16). It is an ongoing debate that leaves the community involved divided.

### iii. Source of Organs

The quintessential ethical dilemma lies in the source of the transplantable organs: cadaveric donors (organs from deceased people), living donors (organs from people who wish to donate) and some potential non-traditional alternative organ sources like stem cells and artificial organs.<sup>2</sup> *“Many, if not most, people agree that taking organs from any source is a justifiable practice within certain ethical boundaries. Controversies result from an inability to define exactly where those boundaries lie”* (Center for Bioethics 2004); (Childress 2001).

The above highlighted issues are intertwined and they largely influence each other. Yet, the formative crux of this thesis is made of issue (iii) which is the ‘source of organs’ for transplant. Among other sources, organs for transplant through trade will be our central focus and area of analysis.

## **I.2 ORGAN TRADE:**

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The act of commercially buying and selling organs or organ trade is seen as a development of expanding organ transplantation and the critical organ shortage faced in its front. The shortage in question being universal in nature has paved the path to International organ trade, with many patients travelling to areas where organs are obtainable through commercial transactions.<sup>3</sup> The international organ trade is “described in terms of its forms: the organ-exporting countries, the organ-importing countries and its outcomes and consequences” (Shimazono 2007). On legality of organ trade, it is essential to note that

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<sup>2</sup> These are potential sources that researches have begun to consider as non-traditional methods, but has not been successful options yet.

<sup>3</sup> Cross border organ trade is called Transplant tourism (Shimazono 2007, 955)

between 1965 – 2012 over 127 countries passed legislations prohibiting the said act of commerce (Amahazion 2016). And as of today, Iran remains the only country to have resorted to a paid transplant system (AH, et al. 2009).

Despite the illegal status of organ trade there is prevalent global market for the same especially with respect to kidneys, considering its scope for living commercial donors. The flow of organs, esp. kidneys in global trade has been traced from developing countries to developed countries.

The following map as retrieved from *Organs Watch* represents countries selling & buying kidneys:

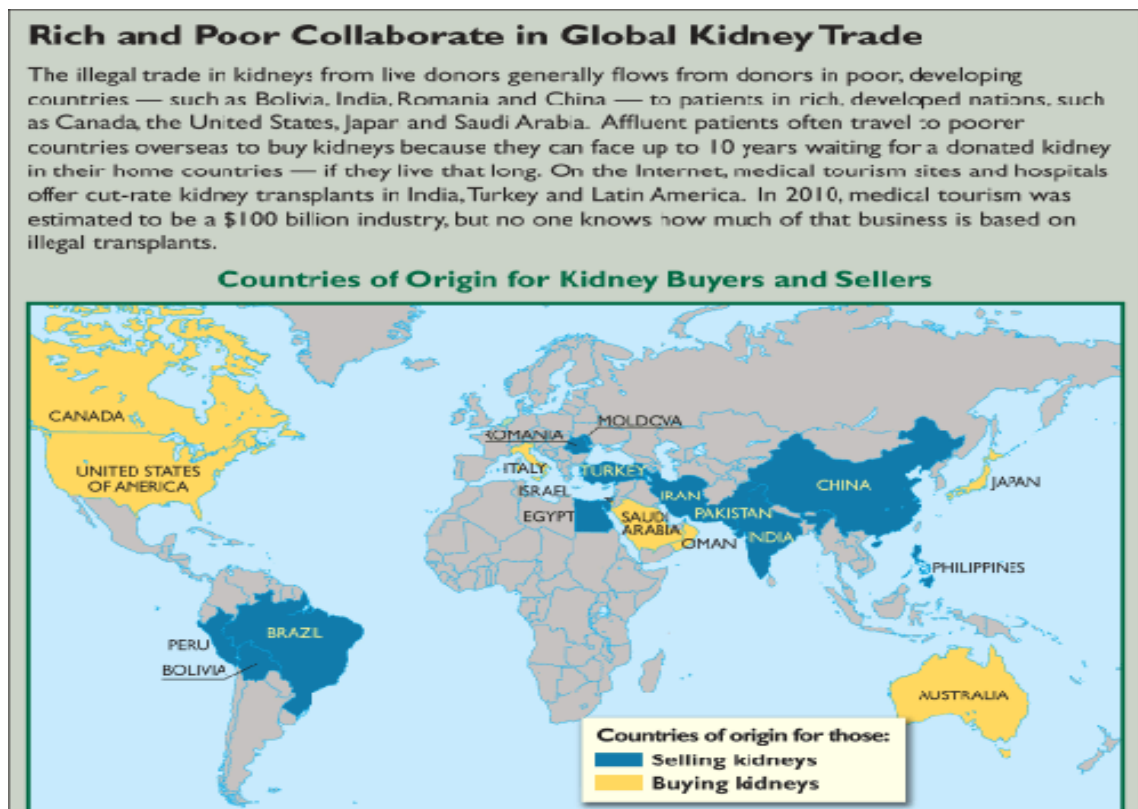


Figure 1: Global Kidney Trade Map (Agrell and Glazer 2011)

“A typical/average kidney seller in a developing country is expected to be a male under the age of 30yrs with a family income less than \$500 a year; while a typical/average buyer in a developed country is expected to be much older with a family income above \$50,000 per year.” (Scheper-Hughes 2005).

And as highlighted in the figure above, India, Pakistan and China are among the commonly known organ exporting countries. While USA, Canada, Australia and Japan are among the commonly known organ importing countries. As much as the arrangement appears to be aligned with a primary principle of Economics – “*Trade can make everyone better off*” (Mankiw 2008) providing for the organ shortage in the front of organ trade, can be followed by several shortcomings. Primary concern remains the ethical stance on organ trade – Is it ethical to sell one’s organ? Subsequently, legislation across the globe seized to support organ trade (Amahazion 2016). Above all, the evil that shadowed the global trade for organs - organ trafficking, became a major challenge in the face of human rights and ethics. “Human organ trafficking has become an industry, and it is growing rapidly under the force of globalization” (Cho, Zhang and Tansuha 2009). “*Payment for organs is likely to take unfair advantage of the poorest and most vulnerable groups, undermines altruistic donation and leads to profiteering and human trafficking.*” (Ambagtsheer and Weimar 2011). True to these lines, developing nations like India have been facing increased rates of human trafficking for illegal organ trade.

Table 1. Number of human organ transplantations, estimated number of human organ trafficking and estimated size of shadow economy<sup>4</sup> (Cho, Zhang and Tansuha 2009)

Country	* Human organ transplantation	** Shadow economy (%)	Human organ trafficking
India	2132	35	746
Pakistan	310	35	109
China	2292	35	802

The data represented above was collected during the 1990s. Considering the lack of available empirical data on organ trafficking, authors Hyuksoo Cho (Korea), Man Zhang

<sup>4</sup> Illicit economic activity existing alongside a country's official economy, e.g. black market transactions and undeclared work.

Notes: \* Yearly average numbers of kidney transplantations during 1990s. \*\* Ratios of shadow economies to GDPs during 1990s. (Cho, Zhang and Tansuha 2009)



(USA), Patriya Tansuhaj (USA) in 2009 estimated the size of illegal human organ trades using available information on ratios of shadow economies to GDPs and size of legal organ transplantation. The estimation empirically proved the magnitude of organ trafficking in countries like India, China and Pakistan. Considering that Iran is the only country where organ trade is legal, with restrictions to limit transplant tourism (Griffin 2007) it has thus far been established that India has been an organ-exporting country in the front of illegal organ trade. Further, it has been empirically proven that the nation faces sizable organ trafficking<sup>5</sup> (Tomlinson 2015).

### **I.2.A. ORGAN TRADE IN INDIA – The policy problem**

Organ trade as an idea could be sold to developing nations, since its people would come forward and donate their kidneys so they can improve their economic status which would in turn increase the number of kidneys available in the global market. The developing democracy of India was lured by the idea and in no time not only did its people become donors for the money but regressively the nation became a market for organs, predominantly kidneys. The country sold kidneys to various parts of the world. Price for a kidney seller in India was quoted at 1000\$ in the 90s (Chengappa 1990). The general dictum subsequently became “*why donate, when you can buy one?*” (Shroff 2009)

Unrelated kidney donation from economically weaker sections for commerce became a common phenomenon and posed as an eyesore in the face of bioethics.<sup>6</sup> It has become evidential that social problems such as poverty and unemployment had motivated voluntary selling of kidneys (Goyal, Mehta and Schneiderman, et al. 2002) and even worse, instigated crimes including human trafficking for organ harvesting (Tomlinson

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<sup>5</sup> Data presented in Table 1 from the 2009 work of authors Hyuksoo Cho (Korea), Man Zhang (USA), Patriya Tansuhaj (USA) project the estimated size of human organ trafficking in India.

<sup>6</sup> Study, concerned with the implications of medical procedures, technologies and treatments from the perspective of ethics, philosophy and law. (Koch 2012)

2015). Lack of awareness and illiteracy among the poor only served as a catalyst to further exploitation.

### **1.2.B. BAN ON ORGAN TRADE – The Policy**

Government of India in the year 1994, imposed a ban on organ trade. The policy made unrelated transplants illegal and deceased donation a legal option with the acceptance of brain death. The policy advocated that by tapping into the pool of braindead patients and accepting donations from relatives of the patients for transplant, the problem of organ shortage can be overcome and this would also curb the commercial unrelated transplant activity i.e. organ trade (Shroff 2009).

#### **The Law: Transplantation of Human Organ Act (THO) 1994**

Ministry of Law, Justice and Company Affairs (Legislative Department)

“An act to provide for the regulation of removal, storage and transplantation of human organs for therapeutic purposes and for the prevention of commercial dealings in human organs and for matters connected therewith or incidental thereto.” (Ministry of Law, Justice and Company Affairs 1994)

Sub Clause (3), Clause 9 of Chapter II of the THO act states *“If any donor authorizes the removal of any of his human organs before his death under sub-section (1) of Section 3 for transplantation into the body of such recipient, not being a near relative as is specified by the donor, by reason of affection or attachment towards the recipient or for any other special reasons, such human organ shall not be removed and transplanted without the prior approval of the Authorization Committee”*<sup>7</sup>

India passed the law to ban commercial transactions for organ transplant in the year 1994.

However, ‘health’ is a State subject in India. Hence, all states have their own departments undertaking the policy formulation with respect to Organ Transplantation. The implementation of the Act discussed above, happened at different points across different

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<sup>7</sup> Government of India. 1994, Transplantation of Human Organs Act, 1994. Central Act 42 of 1994. Bill No.LIX-F of 1992. The Transplantation of Human Organs Bill, 1994

states (Parashar Foundation; MOHAN Foundation 2015). Further, important rules to pursue legal transplants came with subsequent amendments to the law in the years 2008 and 2011. In 2008 the composition and duties of the Authorization committee and authorities for removal of human organs were defined and elaborated.<sup>8</sup> Further, in 2011, the amendment included ‘human tissues’ along with ‘human organs’ making commercial transactions for both human organs and tissues illegal in India. The amendment also defined certain terms in the Act such as ‘near relative’ to mean spouse, son, daughter, father, mother, brother, sister, grandfather, grandmother and grandchildren.<sup>9</sup> Since the Act deemed transplant of organs from ‘near relatives’ legal, this definition was seen to be crucial to help eliminate any exploitation of the ‘near relative’ status.

The law has been made stricter and more stringent over the years through such amendments. Albeit the amendments “*every transplant professional in India knows that commercial transplants continue in the nation*” (Jha 2014). And cases of organ trafficking have also been reported to be prevalent and “described as the ‘dark figure crime’ or ‘the iceberg of crime theory’ – where only a small proportion of crime is visible” (Manzano, et al. 2014). Even after the 2011 amendments, there have been several cases of organ scams, kidney rackets and scandals spread across different parts of the country that have been recorded (Jha 2014).

Such cases and reports raise questions about the prevailing policy (Ban). What is the impact of the policy? Is the ban alone sufficient to face the perils around organ trade? If not, what more can be done in this front?

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<sup>8</sup> GSR No.51(E) (Lok Sabha, Government of India, 2008)

<sup>9</sup> Bill No.136-C of 2009 (Lok Sabha, Government of India 2011)

PART II

# WHY THE CURRENT BAN ALONE IS INSUFFICIENT?

POLICY ANALYSIS AND RECOMENDATIONS

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**Abstract:** *The following chapter analyzes India's policy on organ trade. The policy is analyzed under the Institutional Analysis and Development Framework as developed by Elinor Ostrom. The aim is to understand the sufficiency of the policy, present the current status and make policy recommendations.*

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## II.1. STATUS QUO AND POLICY ANALYSIS

The policy to ban organ trade as explained in *Part I* needs to be analyzed in terms of its impact and sufficiency. Since it is a question of causes and consequences it would be appropriate to apply the IAD Framework<sup>10</sup> to aid us in an effective and efficient analysis. The IAD framework is the Institutional Analysis and Development Framework; it was developed largely by Elinor Ostrom and her colleagues at Indiana University. It is a pragmatic multidisciplinary approach to studying ‘Public Policy’ that is capable of encompassing multitudinous patterns of human interaction. This framework can be used on implemented policies and policies under formulation.

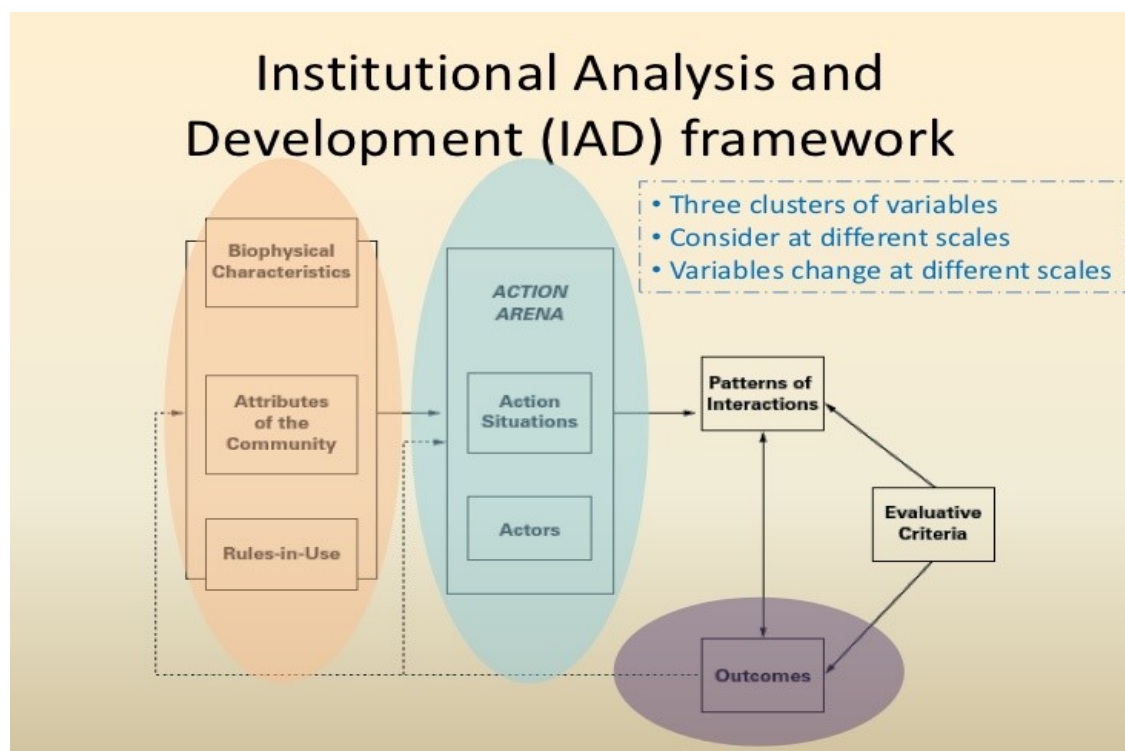


Figure 2: The Institutional Analysis and Development Framework (Huang 2011)

The framework depicts three clusters of variables and traces its situations, interactions and outcomes. The first cluster is made of the physical and material conditions relevant

<sup>10</sup> The author (Ramesh, Pavithra) has applied the framework to the topic in her Public Policy Essay – winter 2015. Yet, this is a more extensive and detailed application with a different approach, conclusion and solution.

to the policy and the second cluster is made of the actors and their action situations that influence the policy. Further, the aspects of the two clusters and the interactions between them are analyzed, thereby reflecting upon the outcome – which forms the third and final cluster of the framework. (Araral, et al. 2012) The framework helps list all the actors, institutions involved and understand where they stand in the policy process. Applying the IAD framework to analyse the said policy stimulates careful thinking about a wide assortment of issues that are important aspects of the policy problem and their influence.

Since our enquiry is on an implemented policy and the aim is to identify what went wrong, the approach to this analysis will be to trace the framework backwards – From the “Outcome” to the “Exogenous variables”. *“When we analyse outcomes, we are really analysing the performance of a policy system.”* (Ostrom and Polski 1999, 25). Analysing the “outcomes” is a comparison between the state of organ trade prior to the policy and the status quo, post the implemented policy. And to make this comparison it is crucial to record the current status of organ trade in India.

### **II.1.A. STATUS QUO**

Organ trade in India remains illegal as of today. The act permits donations from ‘near relatives’ and donations “... *by reason of affection or attachment towards the recipient or for any other special reasons*” (*The Transplantation of Human Organs and Tissues Act 1994*). But, commercial transactions for any form of organ donation is illegal. “Yet, the trade, having gone underground, continues to flourish” (Haagen 2005). There is still a demand-supply gap with respect to organs and especially kidneys. In India, among all the patients who need a kidney every year only around 3% of them receive one for transplant. “This demand - supply gap for donor organs paves the way for illegal transplant and trade of human organs in India.” A recent WHO report records “that in India, around 2,000 Indians sell a kidney every year.” (Masoodi 2015)

Annually, during the month of July, the National Crime Records Bureau (NCRB) of India which is an agency of the Government of India and part of the Ministry of Home Affairs publishes the statistics of ‘Crime in India’ as the official body that collects, analyzes and publishes data on crime in India. The most recent publication ‘*Crime in India, 2015 Statistics*’ as published on July 2016 provides the following information about registered cases under the Transplantation of Human Organs (THO) Act, 1994.

*In the year 2015, a total of 15 cases were registered under the Transplantation of Human Organs (THO) Act, 1994.*<sup>11</sup> *The percentage of pending cases under the act (case pendency percentage) is provided as 100%*<sup>12</sup> Implying that all the cases registered thereof are pending, undecided or undetermined and have not been acted upon.

Table 2: The Number of cases registered under the THO Act – A State-wise representation<sup>13</sup>

S.no	State/Union Territory	No of Cases registered
1	Karnataka	12
2	Punjab	1
3	Tamil Nadu	1
4	West Bengal	1
<b>Total Number of cases registered</b>		<b>15</b>

It is key to note that these are just the *registered* number of cases against illegal organ trade across the nation. The state of Karnataka is seen to have had the most number of cases registered in the year 2015. And all the 15 cases registered remain pending,

<sup>11</sup> Page 40, Table 1.12 in the ‘Crime In India, 2015 statistics’ (NCRB 2016)

<sup>12</sup> Page 194, Table 6.3 in the ‘Crime In India, 2015 statistics’ (NCRB 2016)

<sup>13</sup> Data retrieved from Page 55, Table 1.13 in the ‘Crime In India, 2015 statistics’ (NCRB 2016)

reflecting the delay in action for cases of such nature. And further, of the 15 accused cases, 6 have been registered to be in custody while 9 have been granted bail<sup>14</sup> for the crime accused thereof. This reflects the severity with which cases of the nature are dealt with. Above all, it is essential to highlight that research work on the subject indicate that only some cases of organ trade are reported or registered<sup>15</sup> implying that more cases of illegal organ trade go unregistered.

It is almost appalling to highlight that there are several instances where organ sale has been advertised in the internet. Sometimes these advertisements are available on websites like e-bay: *“We will find kidney for you no longer than seven days, just contact us and say what you want, then we will send you a donor's medicine file and his/her picture, and then remain only the price and conditions for exporting the donor to you.”* (Dr. Srivatava 2013) Apart from e-bay advertisements there are websites that facilitate buying and selling of kidneys for example ‘kidneykidney.com’ which promises to provide for other organs as well. The participation of Indians in the website has been prominent. Here is an enquiry from the website: *“How I can donate kidney? Which are the hospitals in Maharashtra from where I can get the information of cost of kidney, any problem to human if he is having one kidney??”* (Nanaware 2016) Even though data on accurate number of illegal organ trade occurrences is unavailable, its prevalence even in the recent years has been recorded.

***Inference 1: A Market for illegal organ trade prevails even after two decades post the ban on organ trade***

Beyond organ trade and commercial organ transplantation, several cases of organ

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<sup>14</sup> Page: 374, Table 12.6 in the ‘Crime In India, 2015 statistics’ (NCRB 2016)

<sup>15</sup> The Global traffic in Human organs by Nancy Scheper-Hughes; Paid transplants in India: the grim reality by Vivekanand Jha.



trafficking, particularly kidney scams and rackets have been reported in India every now and then.<sup>16</sup> Here is an example of one such scandal that was exposed. On June 5, 2016 the Economic times newspaper, India reported that *“Delhi Police had cracked a kidney racket operated by a group that included the personal staff of doctors at the Apollo Group of Hospitals.”* (Kumar 2016). This came as a shock since the Apollo Group of hospitals are reputed in the nation’s medical field. In the same week (June 8, 2016) an alleged kingpin of the above mentioned racket involving the same group of hospitals was reportedly arrested in Kolkata. (Press Trust India 2016). Such and similar rackets have been exposed time and again. But, this particular incident causes alarm due to the names associated with the racket. Even though, there were reports about the said Apollo hospital being duped into the racket (Reuters 2016). *“The Apollo incident also raises concerns regarding involvement of reputed private healthcare institutions in such rackets.”* (First Post 2016). Additionally, there is concern about the checks and balances in place to ensure legality of the donor. The donor is required to either be related to the patient or willing to donate out of affection or special reason. The question arises about how this can be effectively verified, since most cases reported suggest that fake identification documents were used to prove the legality of the donor. *“‘While all precautions were taken, fake and forged documents were used for this racket with a criminal intent,’ said a statement from the hospital sent to the Thomson Reuters Foundation.”* (Reuters 2016)

***Inference 2: Cases of organ trafficking are still prevalent and widespread***

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<sup>16</sup> A whole list of Kidney scams have been published in the media across the nation. *“Kidney Thefts Shock India”* as reported by Amelia Gentleman in the New York times; *“Stolen kidneys in India”* as reported by Jason Overdof in the News Week. Apart from International media reports, National and regional media and publications have continued to report and record such crimes. Examples are *Murder and Kidney Commerce, A Case of Organ ‘Theft’, A Racket in Karnataka, Gurgaon Kidney Scandal, Case of fake donors in Punjab reported in the Tribune, The Hindu, The express* and several Television Media/News channels between 2000 to now. (Haagen 2005)

Now that the status-quo on the issue has been recorded, the **Outcomes** of the policy and policy system or the third cluster of the IAD Framework can be analyzed.

### **II.1.B. POLICY OUTCOMES – An Analysis**

**Outcomes – Cluster Three:**<sup>17</sup> can be analyzed with a comparison between before and after policy implementation. Before the passage of the Transplantation of Human Organs (THO) Act, 1994 “India enjoyed a comfortable place and a successful legal market in International organ trade. Different groups of stakeholders who were a part of the trade in India had tasted the fruit of revenue from that space” (Koplin 2014). After 1994, the ban changed the status of organ trade to illegal; but did it dissolve the market for organ trade? From the above recorded status quo, it is evidential that despite the ban a market for organ trade exists and is functional. And, there are a list of problems that arise from the given situation. For example “*The traffickers allegedly lure poor people into selling their kidneys for ₹3 lakh and then re-sell the organs on the black market at huge profit.*” (Reuters 2016) In the event that the poor people who agreed to such terms are exploited they are unable to formally lodge a complaint against the middlemen or doctors/medical officers involved in the commercial transplant since it is banned. Following is the response Mr. Balasubramani received when he approached the State Human Rights Commission to claim the money his organ donation was assured:

*“The State Human Rights Commission has no jurisdiction to entertain the complaint of M.R. Balasubramani (donor). Since Section 19 of the Act makes it clear that no Donor of his kidney can claim payment of money. Further, in his affidavit dated 13-12-2001 sworn in the presence of the XXI Metropolitan Magistrate, Egmore, Chennai-8, the donor has specifically stated that “there was no monetary consideration”. (...) He also points out that since the complainant – M.R. Balasubramani (donor) has prayed for payment of the balance amount of Rs. 1,05,000/- (Rs. 1,50,000 – Rs. 45,000 = Rs. 1,05,000/-), which is prohibited under section 19 of the Act, the same cannot be taken note of and enforced by the State Human Rights Commission” (Haagen 2005)<sup>18</sup>*

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<sup>17</sup> Refer Figure 2: The Institutional Analysis and Development Framework (Huang 2011)

<sup>18</sup> “Writ petition Nos. 40101 and 41806 of 2002, W.P.M.P. NOs. 59587 and 61806/2002 and WvMP No. 393/2003, section 4 and 11” (Haagen 2005)

On the one hand, the market for organ trade continues to function. While on the other hand, poor willing sellers who participate in the illegal act can be exploited by the middlemen. Beyond concerns about the existing illegal market and exploitations around it, there are no records or data available on this front to enable a study on the intensity of the issue. This is because “*such offence was non cognizable offering very less penalty amount of Rs 10, 000 and of five years punishment*” (Dr. Srivatava 2013). Non-cognizable offence corresponds to offences that the police cannot independently launch investigation against or make arrests without warrants. It is also indicative of non-urgency in the issue. (Law Baba 2015). It is only after the year 2014 that cases registered under the THO Act<sup>19</sup> were recorded under cognizable crimes, described as crimes against the body and were made available by the NCRB. (NCRB 2016)<sup>20</sup> This explains why there is a 100% pendency rate in these cases(Footnote: 12). For, they are all cases that have been registered post 2014 with ongoing investigations and there is no data for cases registered before the year when they were non-cognizable. Thus due to lack of available data prior to 2014, it is not possible to compare the intensity of organ trade before and after policy implementation. But, the continued prevalence of the practice of illegal organ trade and a market for the same can be recorded.

*The policy in discussion was implemented to ban commercial organ transplant; its rules and amendments highlighted the objective to promote deceased organ donation. Despite criticisms about parts of the content being confusing and wordy, some of the sections were widely appreciated and considered progressive. For example, “Clear definition of ‘Deceased Donor maintenance costs’ and inclusion of a transplant coordinator to give hospital a license for undertaking transplantation” (MOHAN Foundation 2014).*

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<sup>19</sup> Transplantation of Human Organs Act, 1994

<sup>20</sup> National Crime Records Bureau

It is thus, essential to understand the outcome of the policy with respect to impact in deceased organ donation rates. Organ donation being a voluntary act requires pledging of organs by living or deceased “*Deceased donors are most often individuals who die from accidents, heart attacks or strokes, and their next of kin consent to organ donation.*” (Kidney Link: Your Transplant Navigator n.d.) India’s deceased organ donation rates were particularly low before the rules and amendments. Deceased organ donation rate has been the highest in Spain where more than 34.4 per million population (PMP) agrees for organ donation after death, as against a 0.05 PMP in India; this data is as of the year 2012. (Sinha 2012).

But, the year 2015 has seen an increase in deceased organ donation rate throughout India.

Table 3: Deceased Organ Donation Statistics 2015 – State-wise representation (Shroff 2016):

State	Number of donors	Organ donation rate (per million)	Kidney	Liver	Heart	Lung	Pancreas	Intestine	Hand	Larynx	Total organs
Tamil Nadu	155	2.1	290	149	51	28	0	1	0	0	519
Kerala	76	2.3	132	61	14	2	1	1	4	1	216
Maharashtra	60	0.5	106	51	5	0	0	0	0	0	222
Telangana and Andhra Pradesh	98	1.2	168	99	19	7	0	0	0	0	391
Karnataka	60	1.0	91	55	11	0	1	0	0	0	158
Gujarat	45	0.7	77	45	0	0	0	0	0	0	167
Madhya Pradesh	3	0.03	6	2	1	0	0	0	0	0	9
Uttar Pradesh	4	0.01	8	0	0	0	0	0	0	0	8
Delhi-National Capital Region	14	0.3	28	14	6	0	0	0	0	0	48
Puducherry	9	7.2	18	2	1	0	0	0	0	0	30
Chandigarh	39	37	69	25	1	0	2	0	0	0	97
Rajasthan	7	0.1	14	7	1	0	0	0	0	0	22
Total	570	0.5*	1007	510	110	37	4	2	4	1	1675

The increase has been from a previous 0.05 per million population to a 0.5 per million population in 3 years’ time, with the sizable contribution from the states of Kerala and Tamil Nadu. Even though increase is a good sign a 0.5 PMP is still a poor rate of donation.

And Despite this increase, India remains one of the lowest in deceased donors rate with Spain still the highest with 40 per million population as of 2015 (Matesanz, et al. 2017)

***Inference 3: The deceased organ donation rate has increased, but not sufficiently***

## **INFERENCES OF OUTCOME ANALYSIS**

The ban on organ trade changed the status of the practice to illegal. But, is the ban and the legal status of organ trade acquired thereof sufficient? Over two decades have passed since the Transplantation of Human Organs Act was passed. Yet, most reports around the issue read the same from 1990s, through 20014, till today: *“A chronic shortage of organs available for transplant fuels a booming black-market trade in body parts in the country.”* (Reuters 2016). *“Organ Shortage Fuels Illicit Trade in Human Parts”* (Handwerk 2004) It is undeniable that organ shortage is a problem that is being battled world over. (Ginzel, Kraushaar and Winter 2012). But, India particularly, fights multiple battles in this front. *“According to a 2010 Transparency International report, out of 102 countries, India ranked second in kidney trade”* (Bhattacharya 2012).

Thus, there needs to be more focus on this policy problem and the current ban alone is insufficient. The inferences made from the outcome analysis, support the same:

Inference 1: A market for illegal organ trade prevails even after two decades post the ban on organ trade

Inference 2: Cases of organ trafficking are still prevalent and widespread.

Inference 3: The deceased organ donation rate has increased, but not sufficiently

And hence, the scope to further strengthen the policy needs to be explored and to do the same it is important to breakdown the policy and understand its leakages through policy analysis.

### II.1.C. POLICY ANALYSIS

The previous section analyzed the outcomes of the policy system under the third cluster of the IAD Framework. To further understand the policy system and identify its leakages it is crucial to further the policy analysis under the subsequent clusters of IAD Framework. Cluster two of the IAD framework is the Action arena which helps list and map the actors involved in the policy process.

**Action Arena – Cluster Two<sup>21</sup>:** Action arena is the conceptual space in which actors interact. This cluster includes the “action situations and actors (individuals and groups who are routinely involved in the situation)” (Ostrom and Polski 1999, 19).

*A collection of variables* describes the action situations. “The actors; their positions; the set of potential outcomes; information available; costs and benefits associated with the set of outcomes; the degree of control participants have over choices and strategies; finally the relationship between actions and outcomes together determine the action situations” (Ostrom and Polski 1999, 20). Thus, cluster two – action arena helps map the various actors involved and simultaneously analyse their action situations.

- a. **Actors** & b. **Action situations**: The action situations of all the actors involved are discussed below based on the variables listed above.

**(1) Patients in need of organs for transplant** - These are patients battling organ failure and are in dire need of the organ for survival. Hence they are willing to pay a price and buy the organ. Possible outcomes are either they find a willing donor or seek the market illegally. Another possibility is that they lose their lives in the process of waiting. The cost with respect to these actors is the price they pay for their organ, determined by the

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<sup>21</sup>Refer Figure 2: The Institutional Analysis and Development Framework (Huang 2011)

market forces and the benefit is an organ for transplant and thus survival. Due to their willingness to pay for the organ they have certain degree of control over strategies. But there is still a huge uncertainty in finding the matching organ. Their actions influence outcome and sometimes even drive them.

**(2) *Donors willing to sell organs*** – These people are from the economically weaker sections aiming to make some money by selling their organ. They are seen to battle poverty and unemployment to an extent where they are willing to sell an organ to survive. Their conditions are also grave. The possible outcomes are that they donate and get a fair amount of money or they are exploited. Another possibility is that their economic conditions do not get better by the sale but the health deteriorates. Since they are part of the supply chain they have some control over the strategies but that is not much since they do not determine the price for the organ. Their actions directly impact the outcome. Since their willingness to sell results in an illegal act considering that organ trade is banned.

**(3) *Physicians and medical institutions*** – These actors are at the helm of the issue and handle both the supply and demand side. For them an increased number of successful transplants would prove beneficial. The possibilities are that either these actors function justly and ensure they save lives through legal transplants or they ally with groups that mediate and facilitate commercial transaction of organs. Since the rules prescribed by the Law and the Government are carried out by the doctors and medical institutions, the degree of control that they possess is high. They are responsible to ensure that the organs they transplant are not a result of commercial transactions by performing thorough checks on the papers/documents submitted. Since the rules of the act vest the responsibility with the unit and envisions their roles for the purpose of checks and balances. Thus the doctors

and medical institutions performing the transplants can influence the outcome positively by whistle blowing at the sign of any commerce involved or negatively by co-operating in the illegal trade.

**(4) Organ Mafia** – The middlemen and groups willing to take to illegal ways to sell organs so as to make money. Their strength is their connection and ability to sell organs in the market. Possibilities are either they connect willing organ donors and needy patients by extracting profits in the process or kidnap innocents to harvest their organs. The cost they incur is the risk of practicing an activity that the government declares illegal and the consequences there of. The willingness to incur such costs comes from the benefits the practice delivers to the middlemen. The following example reflects on the above statement. *“The BBC reported on an impoverished quarter of the Indian city of Chennai (Madras), known as ‘Kidney District’ because of the high number of residents who had sold organs. One poor woman had earned \$750 for a kidney. The ultimate recipient a Singaporean, paid \$37,000 for it, most of which went to a middleman.”* (Harrington 2000). Since they operate the supply chain they have a reasonable degree of control but it does not favour the common good.

**(5) Government** – It is crucial to understand the form of governance in India. The democratic republic of India practices multi-level governance where the government is elected at the regional, state and National level. Its functioning is supported by the parliament, abiding by the constitution. While Central government oversees the functioning of the state governments and primarily focuses on monetary, fiscal, infrastructural policies etc., most health care and cultural policies are drafted and implemented by the state government. (Lakshmikanth 2014) Each state is an



amalgamation of a variety of communities; the cultural perspective and preference changes in accord to the same. Due to all the apparent differences among the states this form of governance practiced works best for the country. But at the same time, uniform implementation of laws relating to state matters like 'Health' and enforcement of the same become rather challenging. Even though the act banning organ trade was passed in 1994, by the time all the states adopted the law it was 1998 (Parashar Foundation; MOHAN Foundation 2015).

**(6) Civic Sector** – The civic sector synonymously, Non-profit organizations, Non-Governmental organizations, associations and initiatives (Potucek 1999) play a key role in attempting to increase awareness among the civil society about the organ transplant and donation. Some key organizations in India include Multi Organ Harvesting Aid Network (MOHAN Foundation), the charitable trust Apex Kidney Foundation, National Network for Organ Sharing and Multi Organ Transplantation and Human & Educational Research (MOTHER). Such organizations largely work on increasing deceased organ donation rates through awareness campaigns and events. Further, their research work in the field prove invaluable since they collect and present data about donations which would otherwise be unavailable. *Donor rate data published in the year 2014 suggests that the National deceased organ donation rate is at 0.34 per million population for the year 2014 (Navin, Shroff and Niranjana 2016) and subsequently the 2015 donor rate was projected at 0.5 per million population (Shroff 2016).* Thus, the role of the civic sector in creating awareness, presenting research findings and providing for data to gauge the severity of the situation can be highlighted as significant and positively influencing the outcome. *Finally, the role of Media has to be discussed. Media's role in the policy system is more of a regulator than of an actor.*

**(7) Media** – Through the years ranging from pre to post ban, media has taken to the issue of commercial organ transplant, organ trafficking and the perils around the issue with a high degree of sensitivity. Several organ thefts and kidney scams have been exposed by the media. Thus, creating awareness about such instances among the public (refer to Footnote 16 for a selected list of such exposes). But it must be noted that the Media houses and publishers have largely taken a critical stance with respect to the THO Act, with negative articles and coverage about the same. (Haagen 2005). The details of the new rules and amendments were not highlighted or elaborated for public understanding, despite a reception for its progressive parts from the medical society (MOHAN Foundation 2014).

Media has done its part with bringing the crimes related to organ transplant to light and initiating debates on the topic. But, elements of sensationalism have taken away from providing certain knowledge base about the topic and directing the debates towards suggestions or recommendations for the policy problem. It must be concluded that the influences of media as a regulator has been crucial, but not optimal.

The above listed six actors/institutions and Media as a regulator are the key players in the action arena. This summarizes the stances, motivations and circumstances – i.e. action situations of all the actors involved. It is essential to highlight that the current status of organ transplant in India and the emerged outcomes are a result of a journey from before 1994, the year of the ban, till now. And, it is characterized by the interactions between these actors. Analysing the patterns of these interactions could help further the inferences.

#### **Patterns of Interaction:**

The patterns of interactions in policy coordination happens between the actors, institutions from various sectors like market, government, civic & civil sector (to be

referred as civil society from here on).<sup>22</sup> Media acts as a regulator between these actors. Before the ban India had a legal market for organ trade driven by the demand and supply forces of the organ market. Thus the interactions between the market and the civil society had to be via organ trading and organ pricing. In the early 90s the price was estimated to be roughly between \$1000 and \$1200 at the time of sale (Cohen Daedalus 1999 Fall). Market determined the price and members of the civil society buy and sell/trade in the market. Economically weaker sections of the society started to sell organs for money. The patients in need of organs buy the organs for the price.

This describes the interactions between the civil society and the market. Why did this arrangement procure disapproval from the government by way of ban? Apart from the exploitation of the economically weaker sections and the crimes reported around the issue of commercial organ transplant; a need to make an ethical stance on organ trade can be seen as a driving factor in passing legislation against the practice. Between 1965 and 2012 all countries adapted legislation against organ trade from the realm of human rights and ethics; and, India subsequently followed suit (Amahazion 2016). With the inception of the ban, the interactions between the civil society and government can be identified as regulated by media. Where, the Government interacted with the civil society by way of policy implementation and the civil society interacted with the Government by way of representations and complaints; both through Law, order and units of Public Administration. Finally, fuelled by the shortage of organs, despite the ban a black market is created for organ transplant. (Glazer 2011)

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<sup>22</sup> Comprising of the of the civil society, i.e. the public and non-profit organizations, NGOs, trade unions, religious groups etc.

The following figure, is an attempt to trace the patterns of interactions as described above, from the initial stages of the policy (before 1994) till after implementation of the policy:

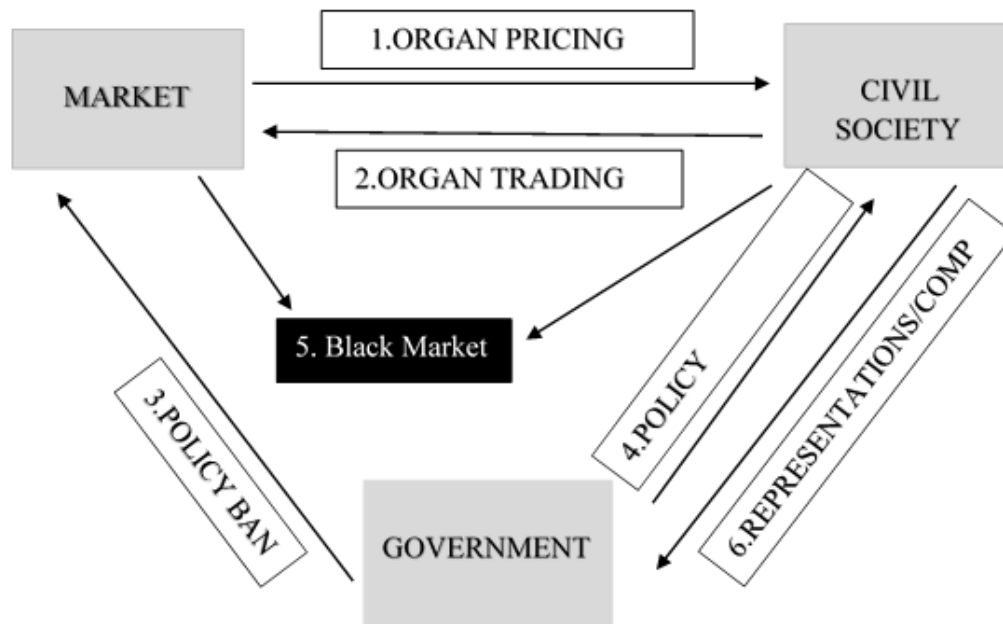


Figure 3: Patterns of Interaction - Organ trade in India

This pattern is arrived at, by tracing the events before 1994 till date. Drawing from the patterns of interactions, (2) organ trade is followed by the (3) policy ban which is then (4) Implemented and yet there is a prevailing (5) black market. Prevalence of a black market despite two decades since the policy ban, suggest a gap in policy implementation and question its effectiveness. Such concerns about the law implementing bodies are further supported by the analysis of the status quo like the 100% case pendency in cases registered against organ trade (refer to footnote 12) and the delay in action against such cases.

***Inference 4: There is a potential gap in policy implementation***

Now that the Outcome (cluster three), Action arena (Cluster two) and the Patterns of Interactions have been analyzed. The final aspect of the analysis under the IAD

framework – Exogenous variables of the Physical and material conditions (Cluster one) has to be analysed.

**Physical and Material Conditions – Cluster One<sup>23</sup>:** The physical and material conditions or the Exogenous variables are assumed to be fixed at the beginning of analysis. There are three aspects to this cluster and they are [a] Biophysical Characteristics, [b] Attributes of the community and [c] Rules in use.

**a. Biophysical Characteristics**

“The physical context, material conditions and type of good under study in the situation are defined as the biophysical characteristics” (Ostrom and Polski 1999). The type of good under study being organs for transplant, the economic situation of the organ sellers makes for the material conditions. While the physical context would be organ shortage and donor crisis as faced in India.

It is crucial to assimilate that the issue of organ shortage is universal. India has and continues to face an acute organ shortage and a donor crisis. *“Shortage of organs for transplantation is a worldwide problem and millions of lives are lost every year because the organ transplantation option cannot be offered to them. In India nearly 175,000 persons develop terminal kidney*

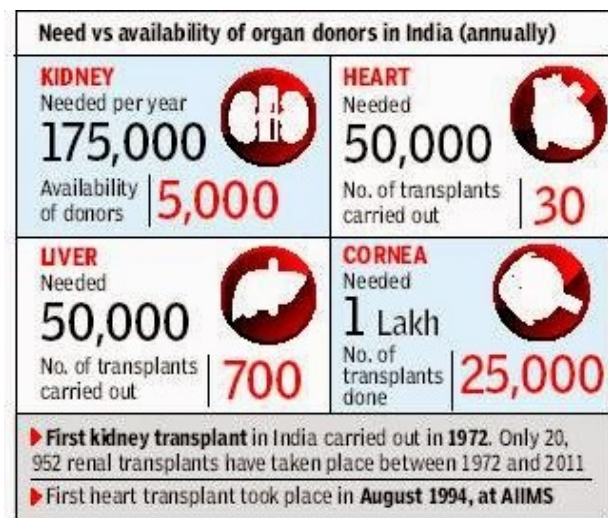


Figure 4: Organ Shortage in India (Parinam 2014)

*failure each year and their life can be sustained only through lifelong dialysis of kidney 10 per cent of them are fortunate to get the benefit of such treatment and the remaining 90 per cent succumb to their condition, often in a short time.” (Sahariah 2013).*

<sup>23</sup> Refer to Figure 2: The Institutional Analysis and Development Framework (Huang 2011)

Adding to the adversities of organ shortage is the nation's poor deceased donor rate. "Of the 9.5 million deaths in India every year, at least one lakh are believed to be potential donors; however less than 100 actually become donors" (Azeez 2015). Deceased organ donation rate as of 2012 was the highest in "Spain where more than 34 per million population (PMP) agree for organ donation after death, as against a 0.05 PMP in India" (Sinha 2012). The physical context of organ shortage and donor crisis; thus made an impact due material conditions which as highlighted above is the economic situation of the population. The World Bank reports that as of 2012, 270 Million people in India are poor. This information translates to one in every 5 Indians leading a life in poverty. Poverty, i.e. people living on less than 1.9\$ a day (The World Bank Group 2015). Under such material conditions, there was potential to convert this section of the population to donor status and meet the soaring demand for organs, if the donation was commercialized. This potential marks the origin of organ trade in India and the beginning of many stories later published such as "*I sold my kidney for 32,500 Rupees. I had to. We had run out of credit and could not live*" (Cohen Daedalus 1999 Fall)

***Inference 5: The root-cause of organ trade in India can be identified as the following [a] organ shortage, [b] donor crisis and [c] willing sellers owing to poverty.***

This raises questions like, was poverty the only reason that encouraged people to sell their organs? How did people perceive and understand organ trade? The second aspect in the cluster of 'Exogenous variables' could help answer such questions.

**b. Attributes of the community**

The attributes of a community that affect a policy action situation include the demographic features of the community, generally accepted norms about policy activities and the degree of common understanding that potential participants share about activities in the policy area (Ostrom and Polski 1999, 13).

The demographic features with respect to the Indian community are vastly diverse. India is a sub-continent that hosts 1.3 billion people spread across 29 states, 7 union territories, 4 distinctly different geographical terrains, numerous religions, culture and tradition. A land where every few hundred KMs the language spoken, clothes worn, customs followed and life led differs staunchly. Beyond the differences, the most influencing aspect of the norms that the Indian community follows are sourced from the religions practiced. Even though a majority follows Hinduism, religions like Christianity, Islam, Sikhism etc. are also among eminent religions practiced.

Despite the heterogeneous nature of the community and general conflict of interests all religions formed a united front in context of the policy activity with respect to organ trade in India. Hinduism, in its theory of creation advocates that the *“humans were created by the gods and that the human body is a temple in itself that is tranquilized by five important elements of air, water, land, sky and fire.”* (Pandit 2001). Christianity prescribes that *‘God blessed them and said, be fruitful and multiply. Fill the earth and govern it.’* (Genesis 1:28)<sup>24</sup>. Islam’s holy book Quran resonates that *‘God creates you inside the bodies of your mothers, in stages, one after another.’* (Qu’ran 39:6)

Since all religions promoted a certain divinity with respect to the human body, the norms of the community did not receive the idea of commercially trading on organs well.

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<sup>24</sup> The Holy Bible

This brings us to the final question about the attributes of the community: What knowledge and information did the participants have? Several sellers who participated in organ trade were highly misinformed. The common belief about living organ transplant, especially kidneys was that it would not have any repercussions or health consequences (Chengappa 1990). The section of the community that were willing to sell their kidneys for money were not educated about the process and thus did not know how to take care of themselves post-surgery. Not only are the sellers unaware about the process, there is a lack of knowledge about the pricing of their organs in the market. “Kidneys are sold by the poor for a small percentage of what they are actually paid for, and this reality leads to the unequal transfer of money” (Jared 2011, 3).

Lack of awareness goes beyond the sellers/potential sellers of organs and their lack of knowledge in organ trade. The community by and large is not aware about the subject of organ transplant or donation. This causes low rates of donations. “There are no structured/focused awareness initiatives or drives to help people understand the what, why or how of organ donation. While some NGOs are making efforts, these are at best – drops in the ocean” (Parashar Foundation; MOHAN Foundation 2015).

Further to lack of awareness, there are several layers of myths that hinder deceased organ donation. Most prominent ones are about brain death. For example: “*people are not aware that it is not possible to recover from Brain Death.*” (Ibid) And thus, the kin are unwilling to pledge the organs of the brain dead for donation.

***Inference 6: There is a widespread lack of awareness about the concept of Organ Donation.***



### **c. Rules in Use**

Among the various types of rules prescribed in the IAD analysis, the following help us present the analysis for the topic in context: (1) Authority rules (2) Information rules and (3) Aggregation rules. (4) Boundary rules

(1) Authority rules specify the actions participants in given positions may take (Ostrom and Polski 1999, 16), such as the set of rules that governs organ trade in India. The rules provided with the transplantation of Human Organs Act, 1994<sup>25</sup> and its amendments in 2008, 2011 and 2014 determine the legality of organ trade in India. Essentially, these rules are the backbone of the policy in discussion – Ban on organ trade. The act and the rules around it as discussed in ‘Part I’ leaves us here with the question about its efficiency and its shortcomings. Even though subsequent amendments in 2014 was well received (MOHAN Foundation 2014) the shortcomings are directed towards the law implementing and enforcing authorities.

The challenges in the implementation phase is due to the inherent setting of the system. Article 246 of the Indian constitution entrusts public health and hospitals under the legislative competencies of the State government (The constitution of India 1949). Considering that organ transplant and issues around it fall under public health; despite the fact that the act to ban organ trade is passed at the central level, each state has its own rules around implementation of the act. There are no uniform set of rules of implementation and the available content has been criticized to be verbose and confusing (MOHAN Foundation 2014).

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<sup>25</sup> The THOA 1994, has been discussed in detail in Pages:

(2) Information rules affect the amount and type of information available to participants in an action arena (Ostrom and Polski 1999, 17). “India does not have any centralized system in place to enable/assist donors or medical institutions. There is no centralized list of potential recipients being available to different hospitals so that organs could reach the right people in time.” (Parashar Foundation; MOHAN Foundation 2015)

(3) Aggregation rules determine how decisions are made in an action situation (Ostrom and Polski 1999, 16). In 2008 the act in concern was amended to incorporate these rules, but “the organ transplant mechanism in India with its rules and procedures in place, is shackled by red tape. Too much of bureaucratise and arbitrariness are the twin problems that block lifesaving transplants in most states in India.” (Sinha 2012)

(4) Boundary rules “can be thought of as exit and entry rules: they specify which participants enter or leave positions and how they do so” (Ostrom and Polski 1999, 16) The Act prohibits unrelated donations only if it is commercial. But permits unrelated organ donations under certain consideration which are rather ambiguous “... *by reason of affection or attachment towards the recipient or for any other special reasons*” The above is an excerpt from the section 9.3 of the Act which is seen be used to exploit and bypass the legality status of the donor. An instance of which was highlighted in the Apollo case discussed in the *II.1.a Status Quo section*. (Reuters 2016)

***Inference 7: Rules in use indicate a lack of [a] uniformity [b] transparency and are criticized for [c] arbitrariness [d] ambiguity in section 9.3 of the act.***

Thus, all aspects of the three clusters of IAD Framework have been analysed. The analysis helped breakdown the policy process and trace the same backwards from the status quo to the aspects influencing the policy. Thereby, arriving at the below set of Inferences.

## INFERENCES OF POLICY ANALYSIS

Out of the 7 inferences made thus far, the first three *(1) A market for illegal organ trade prevails even after two decades post the ban on organ trade (2) Cases of organ trafficking are still prevalent and widespread. (3) The deceased organ donation rate has increased, but not sufficiently* were made from the analysis of the policy outcome and status quo.

At this juncture, it is key to remember that organ shortage is a global issue and it is near impossible to completely eradicate crimes around the issue in India. **But, a parallel black market, widespread organ trafficking and low donor rate, substantiate that the current ban alone is not sufficient.** Thus, implying that the policy needs to be enhanced. Throughout the analysis we have discussed several amendments to the policy. The most impactful were passed in the year 2014:

[a] Post 2014, the crimes under the THO Act have been reported under cognizable crimes. Thus implying an increased attention towards the crime and potential availability of data on registered cases henceforth (NCRB 2016). [b] Despite criticism on the verbose contents, the amendments of 2014 were received well by the medical fraternity, especially the *“inclusion of transplant coordinator to give hospital a license for undertaking transplantation”* (MOHAN Foundation 2014).

Apart from the above discussed amendments, bills to make the punishment against illegal organ trade more stringent have been approved. *“Trading in human organs could soon put you behind bars for as long as 10 years and a fine of up to Rs 1 crore.”* (Sinha 2011)

Despite such amendments and efforts to enhance the policy through the years, why is the current ban alone still insufficient?

To answer the questions, the inferences of the policy analysis have to be discussed:

*Inference 4: There is a potential gap in policy implementation*

*Inference 5: The root-cause of organ trade in India can be identified as the following [a] organ shortage [b] donor crisis and [c] willing sellers owing to poverty.*

*Inference 6: There is a widespread lack of awareness about the concept of Organ Donation.*

*Inference 7: Rules in use indicate a lack of [a] uniformity [b] transparency and are criticized for [c] arbitrariness [d] ambiguity in section 9.3 of the act.*

Inference 4 suggests a potential or impending gap in policy implementation through an analysis of the patterns of interactions and inference 7 solidifies the same. The leakage in the policy process can be identified in the implementation phase with evidences as listed in the final (7) inference. Valuable amendments from 2011 to 2014 discussed above, will fail to deliver desired results if the gap in implementation persists. Thus, we derive from Inferences 4 and 7 that ...

**(i) There is a need to fix the gap in policy implementation.**

And finally, from inferences 5 and 6 we derive the following:

**(ii) There is a need to address the donor crisis and increase awareness about the concept of donation.**

The two key inferences are as listed above. They answer the question ‘Why the current ban alone is insufficient?’ Policy enhancements and recommendations for the same are as provided for in the following section.

## **II.2. POLICY RECOMMENDATIONS**

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Below are the policy enhancement recommendations to cater to the need to fix the gap in policy implementation:

### **1. A uniform approach to organ transplant and issues around it across the nation:**

The Law as highlighted before, has been adopted by different state governments at different times and the approach towards ground level implementation and initiatives taken towards the cause vary. The difference shows varied results; for example, Karnataka is recorded to have the most number of cases recorded under the THO act while Tamil Nadu and Kerala records highest number of donors in India. (Table 2,3). Despite public health being a state subject, the issue of organ transplantation must be treated as an exception; And a common uniform set of comprehensive rules and procedures for transplantation need to be established at a central level and stringently followed.

### **2. Establishment of a centralized body as regulating authority:**

The inception of such a body will enable monitoring and inspection of the procedures being carried out for organ transplantation. The body must have a state level presence and must be vested with a Pan-India jurisdiction. This could ensure effective implementation of the uniform rules across the nation. Further, the 2014 amendment declared an inclusion of a transplant coordinator in the process to give hospital a license for undertaking transplantation. A centralized guidance and training for the such coordinators would prove useful. A uniform set of rules with a centralized system and authority, along with the inclusion of transplant coordinators would present a streamlined process and procedure for organ transplant that would eliminate the much criticized arbitrariness.

### **3. Stringent background checks for unrelated donors:**

Currently, section 9.3 of the act permits donations from non-relatives under “*special reasons*”. To remove the clause from the act would close the avenue for genuine sources of supply, for example donation from a friend, or simply a volunteering donor who is a

match for the patient. Considering the extensive demand, no path to potential supply should be sacrificed. Thus multiple background checks must be in place as against the current procedure of mere ID submissions, so as to ensure that there are no commercial dealings involved. The transplant coordinators must be involved in the process as against the current procedure where the hospital performs mere paper work with submitted ID proofs without vetting the information.

#### **4. The centralized agency/body must maintain a registry:**

The registry must record information of donors, recipients and patients. The information must be optimally utilized and enable a just and equitable distribution. The central body must subsequently develop an organ-sharing network with the participation of government and private hospitals to potentially help avoid any form of organ wastage. The registry and network could be the first steps to transparency in the subject, which would eventually help reduce ambiguity in the legality of donors as supported by the rules and background checks.

The recommendations provided thus far, have been to enhance the implementation of the current ban. These recommendations cater to reducing the illegal organ trade and other crimes and exploitations around it. And, will not render to the problem of organ shortage and donor crisis, which will continue to plague the nation. How can India address the donor crisis? Before making policy recommendations for the issue, a policy alternative must be explored. Should India regulate organ trade to increase the supply of organs and address its donor crisis? The following section will explore the option and make relevant policy recommendations.

PART III

# Why legalizing organ trade is not an option for India?

AN ANALYSIS OF THE ETHICAL STANCE

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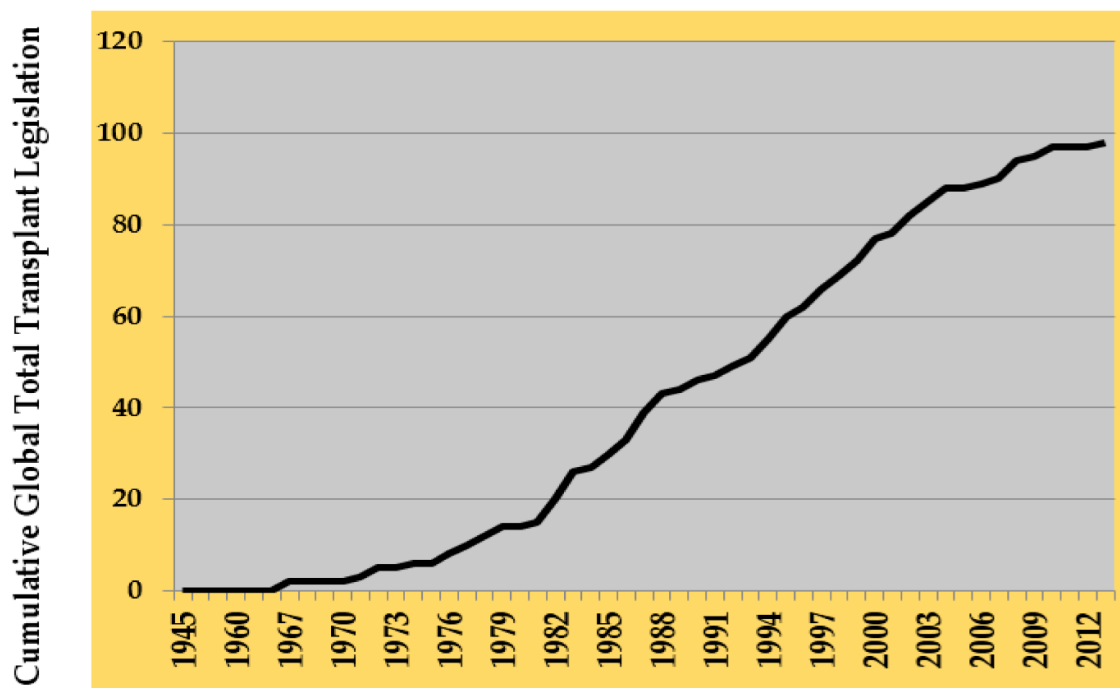
**Abstract:** *The following chapter attempts to explore the ethical stances taken with respect to organ trade. The approach moves from the international perspective to Indian. The Global trends on the legislation and the Iranian model are discussed. And, the concept of DHARMA is applied to the issue and further supported with a survey on the topic from a sample of 215 Indians.*

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### III.1. GLOBAL LEGISLATION TREND

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Before we explore the space of legal organ trade, it is crucial to assimilate the global perspective, approach and trends with respect to organ trade. As recorded in part I, Iran is the only country where organ trade is legal (Griffin 2007) while the rest of the world has passed legislation to ban the act since the late 60s. The first of the countries to pass such legislation have been identified as Chile and Italy in the year 1967. And by 1987 the World Medical assembly which was convened by the World Medical association had adopted a declaration which “condemned the sale or purchase of human organs for transplant” (Fluss 1991, 307). Consecutively, the world saw an increased adoption of legislation against global commercial organ trade.



*Figure 5: Global Legislation prohibiting commercial trade of organs (1967 - 2012) (F. Amahazion 2016)*

The above figure presents the cumulative number of countries (over a 100 countries) that adopted legislation against commercial organ trade between the years 1967 and 2012.



This is a reflection of the stance that the world community takes on the topic of organ trade, which is fuelled by the human rights discourse. The human rights discourse looks upon commercial organ trade as unethical (Haagen 2005). The International human rights regime has been built with a primal importance to *‘Individuals’* and their inviolable rights and the idea is packaged in universalism (Mathias 2013). And *“importantly, these perspectives have become institutionalized internationally through the diffusion of international human rights”* (Amahazion 2016), (Ignatieff 2000). The diffusion of international human rights, influences the ethical stance taken world over, with respect to commercial trade of organs.

*“It is considered wrong to buy and sell human organs, such as kidneys, because it would be immoral to make a profit from the commercialization of such items.”* (Cho, Zhang and Tansuha 2009)

*“Health authorities have been urged to update their legal frameworks...Yet they must also address the underlying problem of organ shortage by using organs from ethically acceptable sources.”* (Shimazono 2007)

*“Urgent efforts are needed to combat organ trafficking and address the issue of an ethical supply of organs to match the demand.”* (Jafar 2009).

Most works in the field acknowledge the problem of organ shortage and urge measures to face the issue. But, there is immense emphasis on these measures being ethically acceptable. Among many global platforms, the WHO in its world health assemblies has consistently advocated agendas to promote donation and presented guidelines for the same (World Health Organisation 2009). Thus, making a statement about dealing with issues of organ transplantation and crimes around it, through ways other than commercial organ trade. The approach continues to stem from the *‘Human Rights’* perspective, describing the act of commercial trade of organs as a *““slippery slope”* (Naqvi 2014); *“dangerous [and] divisive”* (Noel 2014); an *“egregious violation of human rights”* (Glaser 2005) and identifying it is an occasionally raised possible solution” (Amahazion 2016, 159). Predominant global trend on the legislation and ethical stance consistently remain uninclined towards the commercial trade of organs.

Given the context, it is essential to assess India's place in the world community and International arena. As a highly populous and rapidly growing economy, India is in a phase of expanding its global presence. The various bilateral economic ties with countries of South-east Asia, Europe and the US; membership in International organizations in likes of BRICS and SAARC<sup>26</sup>; association and role in IMF, WTO; and frequent diplomatic visits in the recent times by prominent leaders of the country, to different parts of the world (Asia One 2017) are indicative of India's attempts to build its foreign relations and make its presence in the International arena. Adding to which, are its partnership with the European Union (EEAS 2017) and its attempts to seek a permanent membership in the United Nations Security Council (BBC 2004).

*"Instead of trying to avoid engagement with the Great Power system, India now began to seek a prominent place in it... In short, it is naturally inclined to favour building multiple strategic partnerships."* (Basrur 2017). Through its strategic relationships, economic, political and diplomatic ties, India is seen to make cautious and calculated moves to maintain and further build its current position in the Global space. Given which, a move that could un-align itself from the world community and international organizations may not fit well in the Nation's scheme of diplomacy.

Hence, when the global narrative and the International community shows no sign of welcoming commercial trade of organs. To take that path might not entirely work for India. An attempt to regulate or legalize organ trade would be far from its current strategy of cautious and calculated moves. And will be sure to stand out, considering that there is no other country except Iran that has adopted legal organ trade. Therefore, the global

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<sup>26</sup> Acronym for the association between (1) Brazil, Russia, India, China and South Africa (BRICS) and (2) South Asian Association for Regional Cooperation (SAARC)

legislation trend on the said issue and India's positioning in the world community do not provide the nation, with favourable conditions to legalize organ trade.

### **III.1.A THE IRANIAN MODEL**

Throughout the discussion about legislation on organ trade, the striking aspect is the exception of the legal organ trade in Iran. Thereby, raising questions like, why did the country resort to regulating organ trade? how does the Iranian model of legal organ trade function? and What are the impacts of such a regulated organ trade?

*“In 1988, a compensated and regulated living-unrelated donor renal transplant program was adopted in Iran.”* (Ghods and Savaj 2006). The circumstances under which the legislation was adopted, needs to be studied. Iran too, like the rest of the world was faced with acute organ shortage. But the issue was heightened due the backdrop of the 1979 revolution and the Iran-Iraq war soon after. Owing to which “Iran was isolated and economically impaired. Hence, Iran struggled to procure dialysis equipment” (Crepelle 2016, 57). Between 1980 – 85, patients in Iran had to travel to the US and European countries to get a renal transplant and this was funded by the government (Ghods and Savaj 2006). Adding to this, the source of deceased donors was not being tapped until 2002 due to the religious beliefs of the nation that advocated against removing organs out of dead people (Haghighi and Ghahramani 2006). Which implied a much less supply, lack of equipment and mounting demand. “The nation did not initiate commercial transplant with an objective to create a market for kidneys. The exchange between the recipients and providers occurred organically” (Crepelle 2016).

The subsequent question arises about the model and its functioning. The prominent aspect of the model is its elimination of brokers, middlemen or agencies. *“All transplant teams belong to university hospitals, and the government pays all of the hospital expenses of*

*renal transplantation.*” (Ghods and Savaj 2006) The process involves evaluation and appropriate allocation of organs based on the evaluation. This is carried out by a centralized data registry and facilitating body named the *Dialysis and Transplant Patients Association (DATPA)*.

Only when the possibility of living related organ transplant is eliminated, is a patient referred to living un-related, compensated transplant. The donors/providers receive compensation from the Government and additionally from the recipient. In the event that the recipient is not economically sound enough to compensate, charitable organizations compensate the providers. As of 2009, the price a provider received was recorded at approximately \$5000 (Crepelle 2016, 60). The compensation extends to receiving immunosuppressive drugs for subsidized price, healthcare for a year and even a lifetime health insurance in some regions of Iran (Ibid).

Finally, when the impact of such a model is explored, two kinds can be identified broadly. The first being a positive impact is that “*the renal<sup>27</sup> transplant waiting lists in the country was eliminated successfully*” (Ghods and Savaj 2006). As much as this is a welcome change/impact; on the other hand, a majority of the compensated donors have been identified as poor. A study presented “that 84% kidney providers were poor and 16% were middle class. Further, only 6.3% of them had college education” (Crepelle 2016, 63). Which substantiates the prominent argument against commercial organ trade which is the exploitation of the poor; thus bringing the ethical stance and human rights argument back to the foreground.

Based on the elaboration of the background, development, functioning and impact of the Iranian model, it is derivable that it can hardly be compatible for India. Firstly, the nation adopted the regulation of organ market under extreme and unique circumstances,

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<sup>27</sup> Renal – relating to kidneys

elucidating why it remains an exception to the global legislation trend. Secondly, the functioning of the model is largely dependent on the centralized processing, beginning from evaluation, allocation to compensation. A lack of such centralized processing has already been highlighted as the drawback for India. Moreover, it is important to compare the demographics of the two countries. Iran has a population of around 80 Million (Worldometers 2017) as of today. While India has a population of 1.3 Billion (Worldometers 2017). Additionally, the population is far more diverse. If India progresses to establish a centralized body like Iran, the first step would be to facilitate deceased transplants under the model, which in itself is a highly underutilized source with respect to India (Sinha 2012).

Finally, the argument circles back to the ethical dilemma of commercial organ trade. Especially, with respect to the poor and their willingness to part with their organs.

An article named '*The Economic and Health Consequences of selling a kidney in India*' which was published in 2002, attempted to trace the motivation behind the willingness to

	Reason	No. (%)
sell organs among Indians and the consequences of the sale. The study presented results of a survey conducted in Chennai, India, among 305 individuals who had sold their kidneys in the 1990s when organ trade wasn't illegal in India.	Pay off debts	292 (96)
	Food/household expenses	160 (55)
	Rent	71 (24)
	Marriage expenses	65 (22)
	Medical expenses	54 (18)
	Funeral expenses	23 (8)
	Business expenses	23 (8)
	Other debts	49 (17)
	Future marriage expenses for daughters	10 (3)
	Extra cash	4 (1)
	Start business	2 (1)
	Other reason	3 (1)
*Percentages do not add up to 100% because some participants had more than 1 reason for selling or more than 1 source of debt.		

The results indicated that 96% of the respondents sold their kidneys to pay off debts (Goyal, Mehta and Schneidmen, et al. 2002, 1589). This meant that the money acquired via organ trade was not lucratively invested, but were simply expenditure without returns. The sale of organ for money, did not make them economically better off. On the contrary, most respondents recorded that

Figure 6: Reasons for selling kidney (JAMA Network 2002)

they fell back into debt traps. Further, the article also highlighted that 86% experienced deterioration in health status post nephrectomy<sup>28</sup>. Thus indicating that the individuals were faced with “diminished physical abilities to perform labour”. Thereby making them less productive (Ibid. p. 1592).

Moreover, when asked for advice on selling organs, a total of 79% of the respondents said that they would not recommend others to sell a kidney (Ibid. p.1591). To summarize, the economic and health consequences of selling a kidney were represented as negative through the study.

Thus far it has been elucidated that (1) the global legislation trend analysis (2) comparison against the Iranian model and (3) the analysis of the motivations and consequences of organ trade in India, reflect the nation’s incompatibility with commercial organ transplant. Yet, above all it is crucial to probe into the ethical stance that India takes with respect to commercially dealing with organs.

### **III.2. ETHICAL STANCE**

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The quintessential question that remains on the discussion of commercializing organ transplant is the way the country perceives the act of putting a price on an organ and the willingness to be able to part with an organ for money. In short, the ethical stance it takes on the subject. Ethical stances are rooted in the values and norms of the community. In our discussion on the attributes of the community in Part II, it was presented that such values and norms in the Nation, were imbibed from religions which advocated that the human body was a divine gift for humankind (refer pg. 36). Despite norms in the Indian communities associating divinity to the human body, commercialization was still in

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<sup>28</sup> Nephrectomy: involves removing the entire kidney, along with a section of the tube leading to the bladder (ureter), the gland that sits atop the kidney (adrenal gland), and the fatty tissue surrounding the kidney. (National Kidney foundation n.d.)

practice in the forms of illegal trade or trafficking. This can be explained as '*Public Interest Vs Private Interest*'.

Public Interest is defined as "*what men would choose if they saw clearly, thought rationally, acted disinterestedly and benevolently.*" (Lippman 1955) In the case of organ trade in India, the nation saw public interests against the practice binding multiple interest groups together. But, the conflict was that there were diseased patients with organ failures; doctors and hospitals treating them who were benefitting from the supply of organs; donors indulged in the act who saw this as a way to generate income, thus representing the private interests of the actors. Whereas, public interests owed to the greater good and ethical standpoint. "*...testing of behaviour in situations where self-interest and ethical values with wide verbal allegiance are in conflict; Most of the time, the self-interest theory (as I interpreted on Smithian lines) will win*" (Sen 1987, 17). Through the cases of illegal organ trade, the victory of private-interest is reflected. And through the legislation of ban on organ trade the victory of public interest is reflected. To further substantiate that the public interest and ethical stance was against organ trade the theory of DHARMA is applied to the subject in hand.

### **III.2.A. DHARMA**

Though the Dharma is a theory propagated by Hinduism and Buddhism, it works beyond religion and is identified as a significant philosophy of India. Dharma is a theory of morality and social life. "*The word Dharma, which is derived from the root **DHR**<sup>29</sup> (to hold, to support, to nourish) denotes to a large extent and also connotes the same idea as is connoted by the word 'law.'* Dharma in its widest and correct significance implies the attributes or qualities, which indicate inseparable connections between causes and their

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<sup>29</sup> DHR – to uphold everything: humans, animals, nature harmoniously in the universe.

*effects.*” (Sharma 2005, 72) Essentially, Dharma provides for certain code of conduct which is prescribed for different roles. A specific code is prescribed based on the role of the individual – for example *Raja Dharma*<sup>30</sup> prescribes a code of conduct, morality and way of social life for a ruler or a leader. While *Desa Dharma*<sup>31</sup> provides for the duties an individual has towards his country, or the code of conduct of a citizen (praja). Specific codes for every role e.g. son, friend, professional etc. are prescribed by Dharma. Beyond role specific Dharma, there is a way of life and certain general virtues recommended for an individual as part of the human race – *Sadharna Dharma*.

While the role specific dharma is not considered binding, the general Dharma or *Sadharna Dharma* is binding or obligatory for every individual irrespective of their differences. Every individual according to *Sadharna Dharma* is required to cultivate the following general virtues: truthfulness, generosity, compassion, benevolence, sacrifice, non-violence, kindness etc. (Pal 2000) Acts are measured by two notions: Merit (Punya) or Sin (Paap). The Dharma in the act ensures the former. (Sharma 2005). The goal of every individual is thus provided as maximizing Punya. To apply the concept of Dharma and punya to the subject of organ transplant a relevant and appropriate virtue has to be pursued.

Of all the principles and virtues - *generosity* or the art of giving has been largely referenced as Dharma. An individual as a member of the civilization and the human race is expected to give and help the ones in need. This is his/her inalienable and obligatory virtue. On that note, we shall further discuss the act of giving organs to a patient in need and explore the Dharma in the act. The kind of generosity that Dharma propagates is the ‘act of selfless giving’ to promote a righteous living. The ideology can be seen to support

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<sup>30</sup> Raja translates to King or Ruler; Praja translates to citizen

<sup>31</sup> Desa translates to country or motherland



donation (Dhaan). But, the value and merit (Punya) in the donation is determined by two factors (1) The intent with which the donation is made must be *dharmik* - righteous and abiding dharma (2) The results of the donation must be positive and beneficial.

Thus, applying the above to the act of organ donation, we derive that: when a person donates his/her organ selflessly with no expectations of returns but an honourable intention to help. And subsequently, the recipient of the organ benefits from the donation, implying positive results. The donation or Dhaan becomes an act of dharma measured in terms of merit/punya. At the same time, when the donor's intentions are self-interest and commerce; even if the result of the donation is beneficial to the one in need, the act is not supported by Dharma or measured as punya. If organ donation under the two conditions of honourable intent and beneficial results can be deemed as supported by the principles of Dharma. Then, what about the values and norms of the community that attach a sense of divinity to the human body and is considered as gift of nature? Such an approach to the human body, criticizes the attempts to put a price on the organ which is a gift of nature, for commercial benefits. Hence, the principles of dharma combined with values and norms, discourage living organ transplant for money. On the other hand, with its propagation of selfless giving or Dhaan: Dharma encourages the willingness to donate organ without the element of commerce. To substantiate this inference the following excerpt from the Manusmriti<sup>32</sup> is quoted "*Of all the things that it is possible to donate, to donate your own body is infinitely more worthwhile.*" (Sanskriti 2014). Therefore, the principles of Dharma are seen to promote organ donation; and advocate against commercially trading on organs. Given the background, it is important to understand the ground reality and inquire about the perception and ethical stance of the people.

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<sup>32</sup> Ancient Indian Legal text providing for laws of life

### III.2.B. PEOPLE SURVEY ANALYSIS

A total of 215 Indians were asked the following question:

***“What is your stance on being able to sell an organ for money?”***

***[A] It is Ethical***

***[B] It is Unethical***

***[C] It Depends on the situation***

The survey was conducted online for 200 respondents and the remaining 15 respondents were interviewed face to face. The sample of 200 and 15 were randomly picked. The opinions of the former were recorded through a questionnaire circulated online via *Survey Monkey*; while the latter were residents of MGR Nagar, Chennai, India who were interviewed in person. The region was chosen for interview, since the area was home for poor and lower middle-class who worked as labourers, house-help etc. and an online survey could not have reached them.

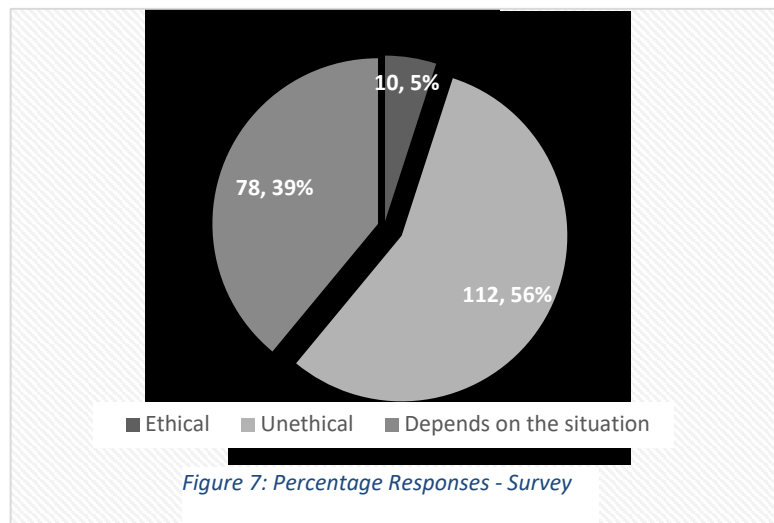
Among the 15 respondents interviewed in person one had sold a kidney to get her daughter married. *“I sold my kidney for 25,000 INR. I was not left with much of a choice. I could not risk marrying my daughter away, without enough gold. Our family had no money and my husband had passed away. No one would lend us money, we had no collateral. I sold my kidney since it was all that I could do. Yet, I certainly don’t think it is an ethical act, but my situation forced me to do the same.”*<sup>33</sup> The other 14 responses were divided between *“It is not ethical, but, If the situation is such and selling an organ is the last resort; one can sell.”* – 9 respondents. And *“It is a sin that cannot be justified”* – 5 respondents. Most narratives opened with *“No one sells their organs with pleasure, it is circumstantial.”* For, they knew someone in their circle who had participated in commercial organ trade.

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<sup>33</sup> A 43-year-old woman who works as a house-help in Chennai, India.

200 respondents recorded their answers by filling in an online questionnaire. They, provided the below presented responses to the question: “*What is your stance on being able to sell an organ for money?*”

A majority of 56% of the respondents find organ



trade unethical and only a minimum of 5% find organ trade ethical; while the rest 39% opine that the stance depends on the situation. Both the online survey and the personal interview reflects that there is a section of people that face an ethical dilemma with regard to the stance on organ trade. Yet, to summarize, most find the act unethical; with a considerable section describing it circumstantial. The principles of Dharma and the ethical stance of the majority reflect the public interests in the subject of organ trade. While the ethical stance of the rest reflects the conflict between public and private interests. Further, when asked if they would support the removal of ban and regulation of organ trade, 97% of the respondents said “No”.

### III.2.c. INFERENCE:

Before inquiring into the ethical stance of the Indian communities and its people, we established the nation’s incompatibility with legal organ trade. The discussion about the ethical stance further supports the same.

To finally answer the question “Why legalizing organ trade is not an option for India?”

[a] It is against the principles of Dharma [b] Study presents negative economic and health consequences [c] The Iranian model is not adaptable in India [d] Legalizing organ trade

would un-align India from the stance that the world community takes on the subject and the nation's current diplomatic strategy wouldn't support the move.

Similarly, in Part I of the paper we established "Why the current ban alone is insufficient?" Owing to [a] The need to fix the implementation gap and [b] The need to address donor crisis and organ shortage. While policy recommendations were made to address the former; the issue of organ shortage and donor crisis remains.

How can India increase the supply of organs for transplant?

The option of legalizing organ trade and regulating the same has been ruled out and all the discussions are directed towards promoting organ donation to increase the supply.

Moving to a more pragmatic discussion, what could possibly motivate a person to part with his/her organ beyond the commercial benefits? When Dharma takes away the commercial benefits, would the value of merit alone be a sufficient motivation for donors?

To answer this, we must list the various possible donations.

Table 4: Possible organ donations under three situations (Azeez 2015):

<b>Brain Death</b>	<b>Living Donor</b>	<b>Other than Brain Death</b>
Eyes & Cornea	Kidney	Eyes & Cornea
Heart & heart valves	Portion of the Liver	Tissues
Lungs	Lob of the Lung	Bone and Marrows
Liver	Portion of Pancreases	Skin
Pancreas		Blood vessels
Tissues		
Pancreas		
kidneys,		
Bones, bone marrow		
Middle Ear and Blood Vessels.		

From the above table, it is evident that the number of organs that can be retrieved from deceased donors (Brain death and other than brain death) are much more than living donors. Thus, a practical solution would be to promote and encourage deceased organ donation. I.e. If the consent to donate is provided during the lifetime, then the donation can be made after death. Beyond the support of Dharma and the Indian conventional approach to human body, deceased organ donation also overcomes arguments on human rights and exploitation of the poor. Thus providing for a suitable and sustainable source of organs for transplant. Moreover, it is a source that India still hasn't tapped.

India has a population of around 1.3 Billion (Worldometers 2017); while its deceased donation<sup>34</sup> rate as of 2015 is at a meagre *0.5 per million population* (Shroff 2016)

Further, *“Statistics shows that 90% of the brain death is due to accidents, especially road accidents. And, according to WHO Global Status Report on Road Safety (2013), India is the country that records over 1,30,000 accident deaths annually.”* (Azeez 2015).

Table 5: Number of deaths in India due to accidents between 2010 to 2013 (NCRB 2014)

Year	Number of Deaths due to accidents
2010	3,84,649
2011	3,90,884
2012	3,94,982
2013	4,00,517

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<sup>34</sup> *“Deceased donors are most often individuals who die from accidents, heart attacks or strokes, and their next of kin consent to organ donation.”* (Kidney Link: Your Transplant Navigator n.d.)

The deaths due to accidents provide for a pool of cadaveric donors who can save many lives. The people who die under such circumstances are potential donors who could increase the supply of organs and help address organ shortage to a great extent. Yet, among the recorded number of accident deaths only less than 3% become donors (Azeez 2015). To increase this rate of conversion the following initiatives are recommended.

### **III.3. POLICY RECOMMENDATIONS**

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Unlike the policy recommendations of Part I, which advocated enhancements to the current policy on organ trade, the following are initiatives and strategies to increase the supply of organs.

#### **1. Centralized awareness campaigns and programs:**

The two major drawbacks in the front of organ transplantation in India is a serious lack of awareness and a lack of centralized initiatives to battle the same. There is a lack of education about the process of organ transplantation and additionally there are numerous myths around the subject, especially related to brain death. Which is the reason why the kin does not consent to donate the organs of the braindead (Parashar Foundation; MOHAN Foundation 2015). These educational campaigns need to be run Nationwide like the “*The Gift of Life Donor Program*” which even facilitates virtual learning through its institute as run by the United Network for Organ Sharing (UNOS) in the United States (United Network of Organ Sharing 2015). There are NGOs in India like KANTI, SHATAYU and MOHAN foundation that run awareness drives and conduct talks/lectures on organ transplantation and being a donor. But these initiatives are limited, few and scattered.

India has been dealing with the issue in hand for over two decades and lack of awareness on the issue is still being flagged. To overcome this obstacle, initiatives need to be large in scale and educational. Further, owing to the demographics, there is a need for such initiatives to be centralized and run by Government. Recent examples of Central Government initiated campaigns like '*Make in India*' are success stories and a similar approach can be adopted for the cause in hand – organ donation.

## **2. Mandated Choice:**

It is a potential strategy to increase organ supply through cadaveric donations. Under this strategy, every citizen would have to indicate their preference towards organ donation to the government. There are two contrasting approaches to reveal such preferences: Opt-in and Opt-out. The opt-in method is called Mandated choice where it is mandatory for a citizen to record his preference in the applications for IDs like voters' ID, driving license or in the tax forms. "The United States practices the opt-in organ donor registration policy" (Barry 2013). While the opt-out method enables procuring organs with presumed consent, where the organ can be taken from the citizens' body after they die, unless a person specifically requests to not donate while still living. On the citizen's death the hospital must comply with the citizen's choice regardless of his/her family's interest. This policy is followed in many European nations (Center for Bioethics 2004).

Of the two, '*Mandated choice*' or opt-in organ donor registry could be best suited for India. For, the benefit of this strategy is that individual autonomy of the organ donor is strongly prescribed. The citizens need to be motivated to make an autonomous choice on this subject with provision of scope for making an informed choice. Opt-in might work better for the nation owing to the Indian communities' sentiments towards funerals and rituals performed after death, especially amongst Hindus who are over 80% of the

population (Understanding Hinduism 2000). And for this reason, presumed interest might not be received well in comparison, at least not anytime soon.

In the year 2009, “the Unique Identification Authority of India (UIDAI) was set up by the Central Government of India in an attempt to assign a 12-digit unique identification number (termed as Aadhar) to all the residents of India.” (Aadhar Card Kendra Editorial Board 2016). This ongoing initiative of the central government is to integrate all citizen information. The preference of the organ donor registration can be mandated in the application for the Aadhar card.

### **3. Incentives for living and deceased donors:**

In order to motivate people to donate organs the following incentives can be considered. Post nephrectomy health care support and related/relevant drugs at subsidized rates for living donors can prove influential. With respect to deceased donors, recognition and gratitude for donation can be recorded in the form of obituary publications. This could motivate more people to come forward and save lives after death.

Apart from the above listed recommendations, the most essential initiative would be to invest in a centralized organizational structure for organ transplantation across the nation.



## CONCLUSION

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Through the course of the study it is quite evident that the nature of the issue – organ trade in India is complicated, deep and layered. Thus the issue is handled at three broad levels with a microscopic approach to analyse the intrinsic aspects of each level. The first level (Part I) provides a background of the subject and discusses the policy and policy problem of organ trade in India. From the understanding of the background, India's ban on organ trade becomes central with the subsequent narration revolving around it.

The narration is furthered with two arguments at consecutive levels. **(1) In India, the current policy ban on organ trade alone is insufficient.** This argument is validated by breaking-down the policy process and outcomes into comprehensible units. The analysis of these units help identify the leakages in the policy process. The second argument **(2) Legalizing organ trade in India is not an alternative policy solution.** Is validated through an ethical analysis from the International Human rights perspective and principles of DHARMA. The inferences arrived at through the two arguments are: **There is a need to (i) fix the gap in policy implementation (ii) address the donor crisis and increase awareness about the concept of donation.** Recommendations to address the two needs are made at the end of each part.

The nature of the recommendations made through this work can be placed between the two extremes of 'Ban' and 'Removal of the Ban' For there is a need to do more than just ban organ trade – which is to fix the leakages in its implementation. Further, there is a need to increase supply of donors without resorting to remove the ban. Hence, the solution is not just a policy ban or removal of the ban. But, the solution lies in the extensive area in-between. Which in context, is described as 'The Grey Area' since its neither black nor white but the extensive area in-between.

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